

CHILDREN WITH AUTISM WEARING ACTION CAMERAS:
CHANGING PARENT/CHILD INTERACTIONS USING
POINT-OF-VIEW VIDEO MODELING

By

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Abstract

Researchers have found that families list interventions targeting the development of social interaction skills among the most sought after treatments for their children with autism spectrum disorder (ASD) (Green et al., 2006). Among the interventions labeled as evidence-based practices (EBPs) for teaching social behaviors to individuals with ASD, is video modeling (VM), a term referring to intervention techniques that provide individuals with opportunities to develop new skills by watching videos, rather than engaging in direct personal experience (Kasari & Patterson, 2012; Reichow & Volkmar, 2010; Wong et al, 2015).

One VM approach, point-of-view modeling (POVM), employs a video production technique that simulates an experience from the vantage point of the viewer and is emerging as an effective intervention (Guta, 2015; Marino & Myck-Wayne, 2015). One possible reason for the popularity of VM techniques is the public's increased access to video production technology and a better understanding about the importance of providing visual supports to individuals with ASD (Knight, Sartini, & Spriggs, 2015; Wong et al., 2015).

Researchers have stated that a way to increase access to autism-related EBPs is to explore more interventions that parents and caregivers are able to implement with very little involvement from service providers (Pickard et al., 2016; Stahmer & Pellechia, 2015). My dissertation research involves the implementation of a parent-provided POVVM intervention created to improve social interaction between parents and their children with ASD. A series of studies ultimately lead to my dissertation study.

The first manuscript entitled "Autism-Related Insurance Mandates: Implications for Evidence-Based Practice" reviewed ways in which language from states' mandated insurance coverage for ASD-related services both supported and acted as a barrier to the implementation of

EBPs. The findings revealed that mandated insurance coverage allowed for positive changes to service delivery in the areas of collaboration, continuous care, and generalization. I also found a need for continued research aimed at creating autism-related EBPS that may be implemented within the framework of mandated insurance coverage, keeping services accessible to families.

The second manuscript, “Social Interaction and Autism: Autobiographical Literature as Evidence” employed a qualitative approach to compare the personal experiences of individuals with ASDs learning about social interaction to recommendations derived from published research. The findings revealed differences between a systematic review’s recommended interventions targeting social interaction and the suggestions from autobiographical authors with ASD about which approaches they felt were most helpful. I found that all of the individuals with ASD wrote about the important roles that their parents played in learning about social interaction, yet very few of the recommended social skill interventions from the systematic review included parents as a part of the treatment protocol. I applied this knowledge to the development of the parent-provided intervention included in my dissertation study.

The third manuscript entitled, “Using Point-of-View Video to Facilitate Social Interaction between a Parent and Their Child with an Autism Spectrum Disorder: A Feasibility Study,” evaluated the feasibility of employing video from a GoPro[®] wearable camera to facilitate communication opportunities between a parent and their child with ASD. The results of this study confirmed the feasibility of designing an intervention that would be practical to implement while measuring effectiveness. This study also allowed me to create and validate a conversational coding structure with strong reliability. Ultimately, this feasibility study provided valuable information that allowed me to conduct a more in-depth assessment of the POVM intervention for my dissertation.

My dissertation study is divided into two manuscripts. The first manuscript reports the quantitative effects of a parent-provided POVM on parent/child interaction. I found that the intervention had positive effects on features of the parent/child interaction, specifically increasing the number of conversational exchanges that *matched* (were cohesive in nature) between the parents and their children with ASD, and increasing the overall duration of parent/child interaction time. I plan to submit the first manuscript to the Technology and the Treatment of Children with Autism Spectrum Disorder. The second manuscript of the dissertation is a qualitative examination of the parents' experiences implementing the parent-provided POVM technique. The findings revealed that the parents had positive experiences using the POVM intervention and gained new knowledge about features of their child's (and their own) social communication. I plan to submit the second manuscript to Focus on Autism and Other Developmental Disabilities.

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successful approaches to overcoming complicated obstacles and her kind willingness to share her time made it possible for me to meet my most important deadlines.

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The Effects of a Parent-Provided Point-of-View Video Modeling
Intervention on Parent/Child Social Interactions

Introduction

Given the increasing prevalence of autism spectrum disorder (ASD), there is a need for evidence based interventions to address core features of the disorder such as social communication difficulties. Research focused on video modeling (VM) continues to explore new approaches to its use as an evidence-based intervention for those with ASD (for review see Gardner & Wolfe, 2013). A growing number of recent studies discuss the benefits of employing VM techniques to support to individuals' with ASDs learning in classrooms (Gelbar et al., 2012; Wilson, 2013), places of employment (Burke et al., 2013), and social situations (Mason et al., 2012; Otero et al., 2015). Among the possible reasons for the popularity of employing VM techniques as autism-related interventions is an increased understanding about the importance of providing visual supports to those on the spectrum (Knight, Sartini, & Spriggs, 2015; Wong et al., 2015).

While research supports the use of VM techniques to support the social communication of those with ASD across contexts, there are also a number of advantages to this particular method of intervention. Specifically, Dowrick (2012) found that the advantages of VM as a learning tool included its feasibility, cost-effectiveness, and the unlimited number of opportunities for an individual to view the successful completion of a task. Videos developed for VM can also be paused, rewound or advanced to review details at a pace best-suited to an individual's particular learning style. Additional suggestions about VM's rising popularity relate to the general appeal of technology to those with ASD and the public's increased access to video recording equipment and editing software (Bereznak et al., 2012; Burton et al., 2013). Additionally, parent-mediated interventions are gaining traction as evidence-based practices (Brookman-Frazee et al., 2006; Pickard et al., 2016; Stahmer & Pellechia, 2015). VM can be

implemented consistently without the presence of a trained therapist; therefore, there may be promise of exploring specific VM techniques as parent-mediated approaches that could ultimately lead to more intervention opportunities and increased child generalization of skills.

The body of VM research is consistently subdivided by three styles of video production (i.e., video modeling of others [VMO], video self-modeling [VSM], and point-of-view modeling [POVM]). VMO involves watching video of another person modeling a desired behavior or new skill. Persons filmed to be in VMO videos may include individuals that are familiar to the person receiving treatment, but are likely to be “actors” that are able to demonstrate the video’s targeted skill with minimal rehearsal so that the video can be produced quickly (Shukla-Mehta et al., 2009). VSM videos are footage of the target individual participating in the successful completion of a task. Compared to VMO, producing VSM videos tends to require more time because the target individual may require supports (e.g., physical assistance, verbal directions) to complete the task. Those supports are then edited out of the final video so that the individual only sees themselves completing the task successfully and independently.

Although parents of children with ASD commonly list the development of communication and social interaction skills as primary concerns when designing treatment plans, researchers have documented the challenges when children with ASD try to learn traditional social interaction strategies (Wong et al., 2015). Many social interaction interventions, for example, have shown limited generalizability across settings (Gantman et al, 2012; Reichow & Volkmar, 2013; Wainer & Ingersoll, 2011). Additionally, individuals with ASD report feelings of anxiety and confusion when learning about traditional approaches to interacting with others, which involve skills such as making eye contact, understanding non-verbal signals, and responding in unpredictable social situations (Grandin & Barron, 2005; Shore, 2005). Therefore,

POVM techniques capture visual information which can be reviewed, serve as a means of exploring authentic lived experiences and minimize the need for traditional communication skills (e.g., eye contact, spontaneity).

Given the possibility that POVM techniques may be efficacious to promote social interaction by more closely mirroring authentic lived experiences, researchers explored the feasibility of a parent and child viewing video from a child-worn action camera as a means of facilitating parent/child interaction (Stump, Dunn, & Tomchek, submitted). In this case study, a child with ASD wore a GoPro[®] camera during a walk inside a favorite shopping center to create a video of his experience. Upon returning home, the child shared the video with his mother and researchers recorded the interaction between the parent and child. Results of the feasibility study revealed that the parent and child interacted longer while viewing video when compared to interactions without a video. There was a corresponding decrease in the number of parent questions while viewing the video, suggesting that watching the video provided the parent an opportunity to ask more specific questions about the experience. Findings also suggested that the POVM technique provided the child a means for communicating about his experience without engaging in behaviors that the child might find challenging, such as maintaining eye contact and producing words without prompts to describe his experience.

Although the abovementioned study showed promising effects, researchers acknowledged a number of challenges associated with generalizing the results of the feasibility study. Future areas of research included the implementation of a process to make parents more familiar with the video recording and playback technologies as well as increasing the number of activities that each participant could video record and discuss. With these adjustments in mind, the researchers concluded that the positive feasibility results warranted more in-depth study to

assess improvements to parent/child communication and interaction time. Therefore, the goal of this study, which built on previous work, was to test the POVM intervention's effectiveness using a single subject design. Specifically, we addressed the following research questions:

1. Does a parent and their child with ASD socially interact for longer periods of time while they jointly viewed a video the child created using a wearable camera (intervention) when compared to their typical daily interactions (baseline)?
2. What are the differences in the key characteristics of the social interaction between the parent and child dyad jointly viewing the video (intervention) compared to their typical daily interactions (baseline)?

Methods

Design

We employed a single subject design and condition comparison. To address research questions, we used a multiple baseline, single-subject design to explore the differences between the durations of parent/child interactions with and without the support of a POV video from a child-worn camera. This design allowed for each participant to serve as their own control. In addition to duration of parent/child interaction, we investigated the structure of interactions using a validated coding system of conversational exchanges between the parent and child in each condition.

Participants

Participants were recruited by word of mouth from the greater metro area of a city in the Midwestern United States. The sample for this study included three families, each with a school-aged (i.e., 5 to 12 years old) child diagnosed with ASD (see Table 1).

Participant 1. Tony was 11 years, 6 months old at the start of the study and of Euro-

American origin. He is home-schooled and participates in variety of activities including karate, chess club, and robotics club. He receives speech and behavioral therapies in his home weekly. He lives at home with his mother, father, and older brother.

Participant 2. Nate was 10 years, 6 months old at the start of the study and of Euro-American origin. He attends fourth grade at a public school and participates in organized soccer and piano lessons. He receives speech, occupational and behavioral therapies in his home weekly, as well as weekly speech therapy at school. He lives at home with his mother, father, and two older brothers.

Participant 3. Collin was 5 years, 2 months old at the start of the study and of Euro-American origin. He attends kindergarten grade at a public school and participates in a youth soccer league. He receives speech therapy at a local clinic weekly. He lives at home with his mother, father, and younger brother.

Additionally, as inclusion criteria, each of the participating families:

1. had a goal to increase their child's abilities to communicate about daily events.
2. had a child with ASD who enjoys watching videos.
3. provided documentation confirming their child's diagnosis of ASD.
4. possessed the technology to watch videos produced by a wearable camera (e.g., tablet, laptop, television, etc.).
5. possessed a smartphone with the ability to record video.

Each of the participating families maintained the frequency and duration of their regularly scheduled therapies (e.g., speech, occupational, applied behavior) throughout the study period. For the purposes of this study, we excluded children with multiple diagnoses or who had frank neurological conditions (e.g., cerebral palsy, deafness).

Settings

Setting for creating POVM video. The activities recorded by the child using the wearable camera took place in a public setting (e.g., public park, grocery store, museum) or at home while the child was away from the parent who would later watch the video. By having authentic experiences on video, we can determine whether this intervention would be useful to families in their own lives outside of scheduled intervention times with professional therapists.

Setting for capturing the parent/child interaction. The family recorded parent/child interaction while watching the video together in the child's home. At the start of each of these sessions, the parent would prompt the child to sit in a pre-determined location (e.g., kitchen table, sofa, etc.) so families could position the cameras to capture the parent/child interaction while also watching the child's POVM video. This process required three devices: Two for recording and one for playing the POVM video. We positioned one recording device in front of the parent and child, allowing for video recording of their interactions from the front (to capture their faces) and another device to record from behind (to capture on-screen content and provide context for the content of their interaction). The third device served as a playback tool for the POVM video (see Figure 1).

Procedures

Each of the three participating families met individually with the first author and completed an approved Institutional Review Board consent document. The families then scheduled time with the first author for brief training regarding technological and procedural aspects of the study. For example, Tony's family was interested to know more about ways to mount the GoPro® cameras and transfer recordings from the cameras to their computer, and Nate's family was curious about activities that would be acceptable to record. We encouraged

families to ask questions at any point during their participation in the study and maintained weekly contact (i.e., phone, email, or in person) to offer support.

Baseline. During the baseline phase, the parents used a single device to record conversations with their child about events that took place during the child's day. We did not provide instructions about these conversations, other than the parents should have these "everyday" conversations with their child as they normally would. After each recorded conversation, we instructed the parent to complete a Parent and Child Conversation – Follow-up Form (PCC) to provide additional information about the interaction (e.g., the child's mood, environmental distractions). We encouraged families to record two to three sessions per week, and collected each families' recordings and PCC forms on a weekly basis.

Intervention. During the intervention phase, the parents recorded the conversations with their child while watching together the video their child produced using the wearable camera. Again, we did not provide guidance about the parent/child interaction, reestablishing that we were only interested in seeing their natural interaction.

Measures

Social Responsiveness Scale (SRS) – Parent Report. The SRS (Constantino & Gruber, 2012) is a parent-reported scale designed to assess social characteristics in children between the ages of three and 18. The SRS utilizes five subscales (i.e., social awareness, social cognition, social communication, social motivation, and restricted interests/repetitive behavior) to create a composite social functioning score. Higher composite scores indicate greater social challenges (i.e., scores of ≤ 59 are considered within normal range; $60 \leq 75$ are mild to moderate range; ≥ 76 are within the severe range). For the purposes of this study, we included scores from the parent-reported scales as background data for the children participating.

Peabody Picture Vocabulary Test-Fourth Edition (PPVT-4). The PPVT-4 (Dunn & Dunn, 2007) is a standardized measure of an individual's single-word vocabulary comprehension. The PPVT-4 is administered by presenting four pictures on a single page and asking an individual to indicate which of the four pictures corresponds with a word the tester speaks. The PPVT-4 provides standard scores that range from 20 to 160, with a mean of 100 and a standard deviation of 15.

Parent/child Interaction Time. During the baseline phase, participant families video recorded the parent and their child with ASD having a naturally occurring conversation about one of the child's activities from earlier in the day. We documented the length of each video interaction as our baseline time variable. We repeated this process during the intervention phase, however, the recordings of the parent/child conversations took place during their shared viewing of the video from the child-worn camera. In both conditions (baseline and treatment) the parent serving as the communication partner used a sentence that acted as our cue to start timing the conversation (e.g., "What happened today?"; "Tell me about this video you made") and a sentence that told us to stop the timer (e.g., "Okay, that's enough"; "Good job, that's it").


Conversational Exchanges Coding. Consistent with the procedures validated in the feasibility study (Stump et al., submitted), we coded conversational exchanges between the parent and child. For example, when the child responded to a parent's question or comment, we referred to the transaction as a *conversational exchange*.

Conversational Coding Key (CCK). The CCK is the instrument validated in the feasibility study to systematically code each conversational exchange between parents and their children. Exchanges were coded to be a *conversational match (M)*, a *conversational match with*

prompts (MP), or a response that *does not match (DNM)*. Appendix A summarizes the criteria used to code the exchanges.

Here is an example of a single coded conversational exchange:


Parent: *What did you do when you got home today?*
Child: *Played cars.*



One exchange, coded *M*

As is common in many conversations, sometimes speakers included more than one comment/question within their turn to talk or spoke during the other person's response. Here is an example, coded as one conversational exchange:

Parent: *What did you wear? Did you wear your jacket?*
Child: *No, I wore my...*
Parent: (interrupting) *You didn't wear your jacket?*
Child: *...No, my sweatshirt.*



One exchange, coded *M*

Data Analysis

To analyze differences in the duration of parent/child interaction times across baseline and intervention phases (research question one), we employed a two standard deviation band method. The standard deviation band method, which is a type of visual analysis, is beneficial over other methods as it is intuitively meaningful and reflects the clinical significance of outcomes (Portney & Watkins, 2008). The two standard deviation band method uses two lines (located one standard deviation above and one standard deviation below the mean data for the baseline phase) drawn horizontally across the baseline and intervention phases. Statistical significance occurs when two consecutive data points are plotted outside the two standard deviation band (Portney & Watkins, 2008). To analyze research question two, we used chi-

square analyses to assess for statistically significant differences among conversational exchanges between the parent and child in each condition as coded.

Findings

Parent/Child Interaction Time

Results indicated that the three parent/child pairs increased the amount of their social interaction time together during intervention versus control conditions. That is, parent/child pairs showed a 39-503% increase in the amount of time spend interacting with a child POV video as compared to a typical daily interaction condition. Table 2 depicts the increased interaction times during intervention sessions and the corresponding percentage increase from participants' baseline times.

Characteristics of Parent/Child Social Interaction

The results revealed changes to the characteristics of parent/child social interactions, with more conversational exchanges coded as *M* (conversational match) while the parent and child shared video from the wearable camera (intervention condition). As displayed in Table 2, chi-square analyses revealed statistically significant differences ($p < .05$) in the distribution of the conversational exchange codes MP (matching with prompts) and DNM (does not match) comparing baseline and intervention conditions. Specifically, during the intervention phase, each parent-child dyad showed increases in the number of conversational matches; two parent-child dyads showed increased 'does not match' and two parent-child dyads showed changes to 'matching with prompts' (one dyad increased and the other decreased). Further thoughts about these exchanges are addressed in the discussion section.

Discussion

Novel findings from the current study suggest that POVM may be a promising method to increase social communication exchanges between a parent and their child with ASD. Regarding the first research question, we found statistically significant increases in parent-child interaction time when the dyad jointly viewed their individualized POVM videos. This finding suggests that when a parent and child share the POVM video, there is a corresponding increase in their joint attention when compared to traditional conversation. Previous research states that joint attention is an essential component of sustained conversation and provides increased opportunities to practice social interaction skills (Charman, 2003; Pickard & Ingersoll, 2015; Sodian & Kristen-Antonow, 2015).

Findings for the second research question demonstrated that parent/child conversations are positively impacted by sharing the POVM video. Specifically, chi-square analyses revealed statistically significant increases in the number of *matching* conversational exchanges between the parent and child. Additionally, the intervention phase resulted in significant differences in the number of conversational exchanges that *did not match (DNM)* and *matched with a prompt (MP)* that introduced additional conversational features.

Regarding *DNM* and *MP* Frequencies During Intervention

Two of the three participating parent/child pairs showed increased occurrences of the conversational exchanges coded as *does not match (DNM)* during the intervention phase as compared to baseline. In each of the coded exchanges, however, the children appeared to use the video as a means of directing the conversation or drawing the parent's attention to the content on the screen. Here is an example of two consecutive exchanges, the first coded as *M*, the second as *DNM*:

Parent: <i>What are you doing?</i>	}	One exchange, coded <i>M</i>
Child: <i>We're racing!</i>		
Parent: <i>Are you going to win?</i>	}	One exchange, coded <i>DNM</i>
Child: (pointing at screen) <i>Ready, set...Go!!</i>		

In this example, the second parent/child exchange is coded as *DNM*, consistent with the structure of the coding key developed and validated for this study. However, analysis with combined transcription with video of the parent/child interaction suggests a potential match. When *viewing* the parent-child interaction video to provide context, it appears that child is attempting to direct attention to the screen so that the parent does not miss the beginning of the racing activity. This suggests that the children are attempting to increase their parent's engagement in the activity by directing attention to the video, rather than ignoring the parent's question. Similar conversational exchanges were noted among the remaining participants' videos. Given the importance of child initiation of joint attention and verbal requests for parent attention (Yoder & Warren, 2001), child POV video as a method of intervention may serve as a mechanism to increase child initiation. While previous studies have shown that parent responsiveness to child interests may increase social communication (Hobson & Hobson, 2008; Landa et al., 2007), the current intervention method may serve as a further tool to increase child opportunities to direct their parents' attention.

MP during intervention. Results showed that two parent-child dyads demonstrated significant differences in the number of exchanges coded *MP* during the intervention phase as compared to the control condition. One dyad (Collin) eliminated *MP* exchanges during intervention (i.e., two to three *MP* expected per session, zero observed) and the other dyad (Nate) increased. Based upon baseline data, we expected the conversations between Nate and his parent

to contain one to two *MP* exchanges per intervention session. We tallied a total of seven *MP* exchanges during Nate's intervention phase, with all seven occurring during one session.

A closer inspection of the intervention session with a spike in the number of *MP* suggests that these coded exchanges may need reconsideration. When coding from the transcripts alone, these interactions fit the intention of the *MP* code. However, when watching the parent-child video, these interactions seemed to reflect the child's attempts to confirm what the parent said, and then extend the conversation into a new topic. Here is an example:

Parent: *I think that's pretty cool.*

Child: *Yeah, pretty cool... Watch this!*

The coding key states that if the child repeats the parent's utterance as a response, that exchange would be coded as *MP* (match, but prompted). As with the *DNM* example above, the video of the parent/child interaction suggests that the child is confirming the parent's observation before attempting to coordinate attention to the *POVM* video.

By reviewing video in conjunction with the transcripts, the research team universally agreed that the parent/child exchanges in these examples appeared to be consistent with our expectations of typical conversation. Our data with *POVM* videos to support interaction seem to be revealing some conversational features that are obscured when analyzing typed transcripts alone.

Summary

The results of this study further develop insights from the previous feasibility study (Stump et al., submitted) and contribute to literature suggesting that video modeling interventions lead to positive outcomes for individuals with ASD. A possible explanation for the positive results of this study is that the intervention activity incorporated self-produced *POVM*

videos that the children (and parents) found interesting. Previous research shows that individuals with ASD demonstrate increases in the quantity and quality of social interactions when given the opportunity to interact about things they find personally interesting (Koegel et al., 2013; Waugh & Peskin, 2015). Because we had not only transcripts, but also parent-child interaction videos, we discovered some natural conversational rhythms that support useful and satisfying exchanges which need further study.

Another important result of this study is that the families completed the intervention activities without the need for regularly scheduled professional assistance. The literature explains that families of children with ASD are commonly faced with complex challenges related to their child's intervention services (e.g., choosing services and providers, scheduling visits, funding) (Goin-Kochel et al., 2007; Mackintosh et al., 2012). Independent family participation, coupled with the positive and statistically significant results of this study, has strong implications for practical application. Aside from the researchers' initial guidance regarding the operation of equipment and procedural aspects of the study, the participant families completed all phases of the study with minimal professional support. Research suggests that by assuming a lead role in the intervention process, parents may decrease levels of personal stress while increasing social opportunities for their child and supporting generalization (Oldfield, 2006; Hobson & Hobson, 2008; Yoder & Warren, 2001). The POVM approach in this study takes steps toward providing families with a successful intervention that can be implemented with intermittent guidance from professionals.

Recommendations for Future Research

1. Complete follow-up studies that assess any long-term effects of increased parent/child interaction times.
2. Consider a more diverse sample of parents and their children.
3. Utilize pre and post evaluations to better understand any effects of this POVM technique on parent/child relationships.
4. Study the conversational exchanges of a child with ASD using the POVM technique across multiple settings and with multiple communication partners.
5. Combine visually coding parent/child exchanges via video with the coding of transcribed verbal exchanges to provide deeper insight into the quality of parent-child interactions.
6. Measure any potential effect of this POVM technique on parent behaviors (e.g., participation in therapies, conversational techniques, etc.).

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Table 1

Participant Characteristics

	Tony	Nate	Collin
Age	11 years, 6 months	10 years, 6 months	5 years, 2 months
Sex	Male	Male	Male
Ethnicity	Caucasian	Caucasian	Caucasian
Grade	Sixth	Fourth	Kindergarten
PCP	Mother	Mother	Father
Diagnosis	Autism	Autism	Autism
SRS Total	68 (moderate range)	61 (moderate range)	72 (moderate range)
PPVT Standard Score	78	112	80

Table 2

Chi-square analysis results

Participant	Chi-square		
	M	MP	DNM
Tony	349.16, $p < .001$	<i>No occurrences</i>	1.5, <i>ns</i>
Nate	10.12, $p = .001$	18.73, $p < .001$	5.41, $p = .02$
Collin	739.23, $p < .001$	7.2, $p = .027$	10.1, $p = .006$

Table 3

Comparison of Parent/Child Interaction Times With and Without POV Video

Participant	Mean length of interaction during baseline (no video)	Length of interaction during intervention sessions (with video) (% increase)		
		Session 1	Session 2	Session 3
Tony	3:18	19:54 (503%)	9:36 (192%)	12:12 (270%)
Nate	6:30	9:06 (39%)	12:12 (88%)	
Collin	2:48	13:30 (382%)	8:31 (204%)	13:24 (378%)

Figure 1 *Camera positioning to record parent/child interactions during intervention.*

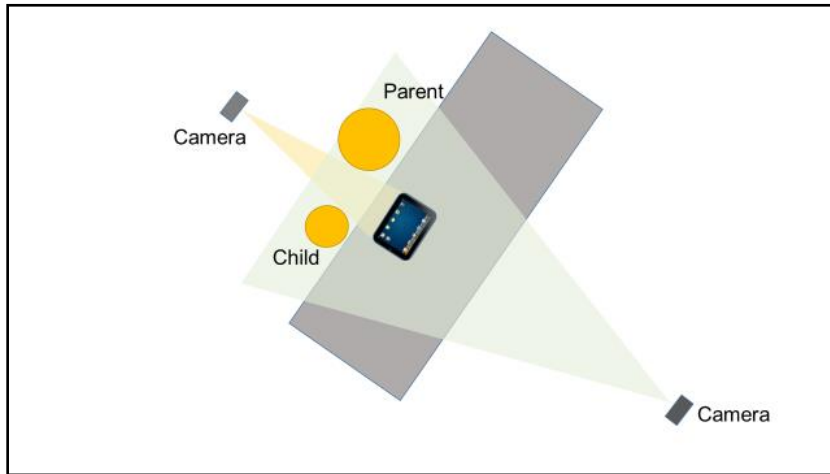
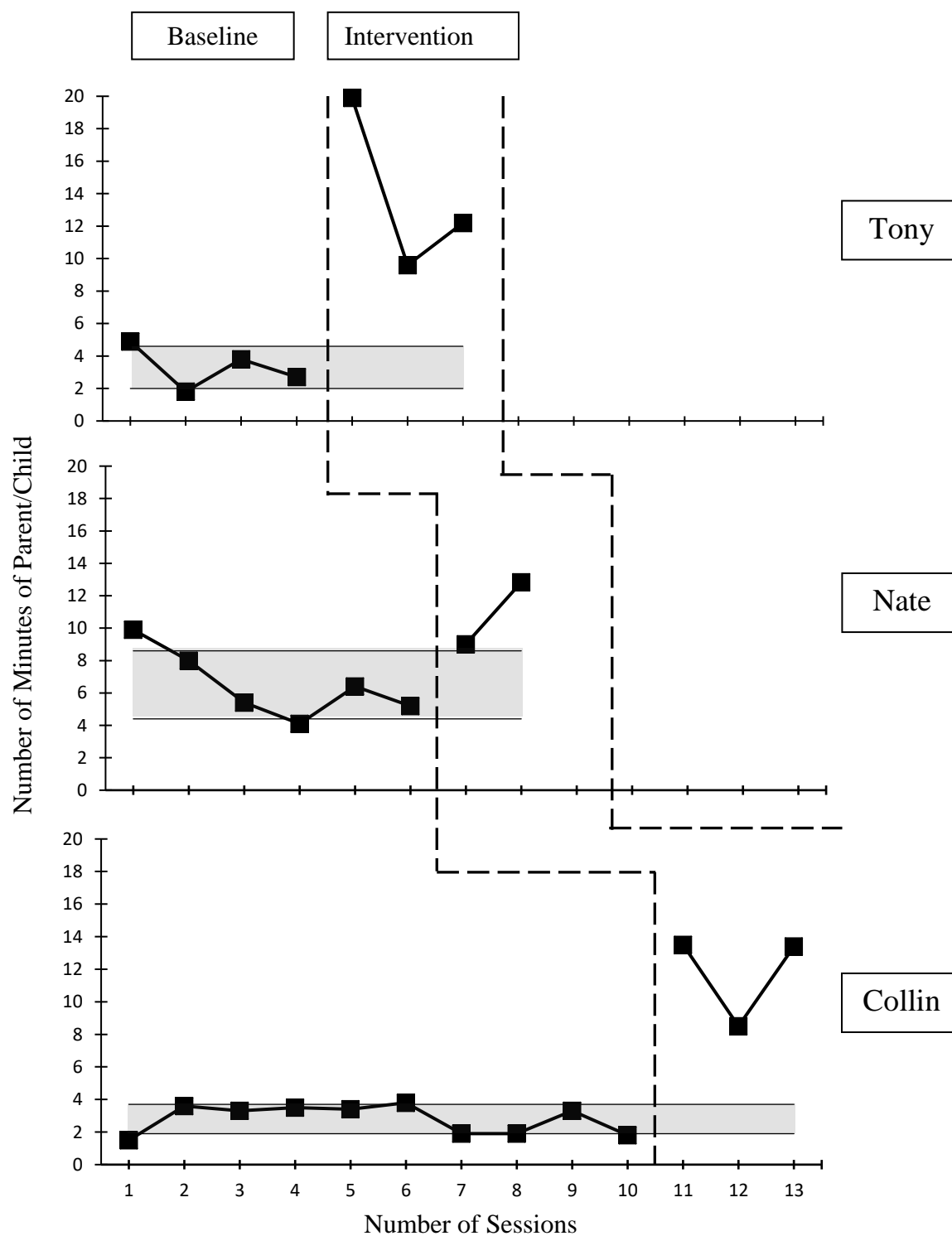


Figure 2 *Multiple baseline graph of parent/child interaction times*



Oh, Now I See!: The Influence of a Parent-Provided Point-of-View Video
Modeling Intervention on Family Social Interactions

Introduction

The value of family involvement in the intervention process for children with autism spectrum disorder (ASD) is well-documented (Mackintosh et al., 2012). Researchers, family members, and individuals with ASD have all written about the important roles families play in the lives of loved ones “on the spectrum” (Goin-Kochel et al., 2007; Grandin & Barron, 2005; Mackintosh et al., 2012). Researchers frequently include parents as supplementary sources of information to measure the quantitative effects of ASD-related treatments for their children (e.g., medical, educational, social) (Stahmer et al., 2016; Wong et al., 2015). Additionally, there are numerous qualitative studies that focus solely on better understanding the parents’ lived experiences as they relate to having a child with ASD (DePape & Lindsay, 2015; Kinnear et al., 2016).

Studies have suggested that parents of children with autism are the primary sources of information for the autism community *as a whole*. In addition to providing guidance for researchers and service providers, parents of children with ASD are frequently sought out by other parents of children with ASD to gain information about successful therapies, community resources and recommendations for service providers. In a 2005 study by Mackintosh, Myers, and Goin-Kochel, the authors found that less than 50% of parents of children with ASD relied on educators and physicians for direction regarding interventions, while 72% of participants cited other parents of children with ASD as their primary guides. Perhaps one effect of this trend is the increased focus on developing more parent-mediated therapy techniques to increase access to and dissemination of best practices (Pickard et al., 2016).

Over the past three decades, a growing body of research focused on video modeling (VM) has led to its recognition as an evidence-based practice for teaching new behaviors to

individuals with ASD (Kasari & Patterson, 2012; Reichow & Volkmar, 2010; Wong et al, 2015). The literature categorizes VM interventions according to three styles of video production: (1) Video modeling of others (VMO), (2) Video self-modeling (VSM), and (3) Point-of-view modeling (POVM). Recently, research has suggested that the public's ever-increasing access to inexpensive and portable video production technology (i.e., smartphones, tablets, GoPro[®] cameras) has created opportunities for assessing VM's potential suitability as a set of parent-mediated interventions (Guta, 2015; Marino & Myck-Wayne, 2015; Reichow & Volkmar, 2010). In parent-mediated interventions, providers train parents in specific programming.

Green et al. (2006) found that families list interventions targeting the development of social interaction skills among the most sought after treatments for their children with ASD. In addition to research addressing VM's efficacy among a range of academic and adaptive skills, a number of studies have found VM techniques to be beneficial for the development of social interaction skills (Buggey, 2012; Buggey et al., 2011; Charlop et al, 2010; Cruz-Torres, 2015; Tetreault & Lerman, 2010). Surprisingly, despite families' stated needs for access to social skill interventions, VM's emergence as an EBP for teaching about social interaction, and the scientific community's recommendations to explore VM as a set of parent-mediated interventions, no studies to date have researched the experiences of parents as direct providers of VM interventions for their children with ASD (i.e., parent-provided interventions). In parent-provided interventions, providers set up a scaffolding for the intervention, and the parents implement the activities as it fits their children's and families' ways of interacting.

Prior to initiating the study profiled in this report, researchers completed a feasibility study exploring the use of POVM video from a child-worn GoPro[®] camera as a means of facilitating parent/child interaction (Stump, Dunn, & Tomchek, submitted). Although the goal

was only to test feasibility, additional findings suggested that (1) the parent and her child with ASD interacted for a longer period of time while viewing together the POVM video the child had created using the GoPro[®], and (2) the parent reported feeling that the POVM video had a positive effect on the overall flow and content of their social interaction.

Purpose

Given the preliminary efficacy of the intervention and associated positive impact of POVM on child/parent social communication, we were interested in parent experiences implementing the intervention. By gaining insight into parental experiences in the intervention process, we may be better able to meet family and child needs in larger intervention trials in the future. Therefore, the goal of this paper was to gain a better understanding of the parents' experiences implementing a parent-provided intervention using the POVM technique.

Methods

Design

This qualitative study analyzed data from individual, semi-structured interviews of three families of children with ASD involved in a larger intervention study. The interviews were conducted as part of a larger study assessing the changes to social interactions between a parent and their child with ASD while watching a POVM video that the child created (Stump et al., in progress). We chose to report these qualitative findings separate from the larger study's quantitative results to allow for a more in-depth assessment of the participants' experiences and to better inform future decisions regarding the intervention's use (Albright et al., 2013).

Participants

We used convenience sampling to recruit participants by word of mouth from the greater metro area of a city in the Midwestern United States. The sample for this study included parents

from three families, each with a school-aged (i.e., 5 to 12 years old) child diagnosed with ASD. We interviewed a total of four parents, two mothers and two fathers, ranging in ages from 34 to 47 years. Although we only required the individual parent who served as their child's primary communication partner during the intervention study to be present for the follow-up interview, both parents from one of the three families chose to participate in the interview.

Procedure

We collected data by interviewing participants in person or by phone, following their respective completion of the POVM study's intervention phase. We used a semi-structured interview format, with open-ended questions created and validated in a previous feasibility study (Stump et al., submitted) as a guide for topics to address. To be consistent with best practice recommendations for semi-structured interviewing, the lead author conducted each of the interviews, taking notes and asking follow-up questions when necessary (Whiting, 2008). Each of the interviews took 30 to 60 minutes to complete and was digitally recorded. The recordings were then transcribed verbatim by members of the research team.

Data Analysis

We analyzed each of the interview transcripts in accordance with the multi-staged thematic analysis methods described by Braun & Clark (2006). After transcribing the interviews, each member of the research team repeatedly read the parents' responses verbatim and independently to familiarize themselves with the content. The team then convened to discuss individual impressions and develop initial codes. This analyst triangulation process utilizes input from multiple analysts to minimize the influence of personal perceptions and better understand alternative ways of processing the data (Patton, 1999). Using the initial codes, researchers were able to generate, review, and define more specific themes from the data. At the

end of the analysis process, each of the study participants was offered the opportunity to review the team's conclusions for accuracy and relevance. Such member checking allows for a greater trustworthiness of qualitative findings by providing open communication between researchers and participants (e.g., Creswell & Miller, 2000).

Results

Thematic analysis revealed three overarching key themes addressing the parents' experiences throughout their participation in the POVM study: (1) *So, this is all up to me?* (2) *I'm still not sure about these cameras* and (3) *Well, I never noticed that!* These key themes and their associated sub-themes are discussed below with participants' quotes to illustrate discussion points (Braun & Clark, 2006).

Key Theme: So, this is all up to me?

This theme reflects findings related to parents' insights about POVM as a parent-produced intervention. Each of the parents spoke about the benefits and challenges associated with being responsible for providing the intervention. One mother described the challenges with finding time to watch the video their child had made during the intervention phase of the study, saying "It's a lot harder than we thought it would be to find time to do stuff like that (watch the video together). I thought it would be fun...and then life happens." This statement underscores the parents grappling with how to fit these new features of the intervention study into their routines. A common challenge the participants cited involved technological aspects of the study. A father stated, "We've never messed with a GoPro®, so it was all new to us.... Maybe (it would help) having better directions on how do you do any of the methods you allow us." Clearly, parents felt as if they needed slightly more support in terms of time and technology planning.

All four parents described lacking confidence in their ability to administer an approach that was new to them and without traditional levels of regular professional support:

I know you wanted it to be kind of coming from us, but if you were looking for more or something different? I felt like kind of we were...just wasn't sure if we were doing kind of what you were looking for?

It was harder for me, as the parent *and* the facilitator, or whatever you call me... whatever my part is. It was harder for me because I was like, 'I'm not used to watching videos of people'...so it was new for *me* too.

One parent spoke about the noticing a shift in the way her son interacted with her when they sat to watch his video, saying:

I think he thought it felt like 'work.' I think he kind of felt like, doing the video, and then talk about the video....I think that that was, he didn't use the word 'redundant,' but that's kind of what I got from him. Like, 'why do we have to do this again? Well, we already, you know, we already talked about this!'

Although parents reported challenges providing the intervention, each parent spoke positively about spending time with their child during the study and developing their own approach to interacting with their child while sharing the POVM video. One father spoke about the intervention as something he looked forward to while away at work:

Obviously, it gives us something to talk about...you know, instead of just coming home and saying, 'So how was your day? What did you do?' and it's just, 'fine' or, you know...we had something to kind of do together. And to get more out of him than just, 'I went to school,' or whatever he did that day. So I guess it helped a little bit with our communication.

Similarly, a mother emphasized the shared enjoyment that occurred during the time spent with her son watching the videos that he created:

It was just so fabulous! I thought I need to sit down and give him time to do this more often! We do talk, but that was really fun. To just...I think the one-on-one aspect of it, like when we're talking at dinner and there's all of us...It was different just me and him talking and me just really asking questions. He ate that up, that was fun!

Key Theme: *I'm still not sure about these cameras.*

Parents reported conflicting views regarding their child's use of a wearable camera to capture the child's experiences. During the interviews, all of the parents expressed excitement about using video from the cameras to gain information about their child from the child's perspective, but that they also worried about the potential for an associated social stigma. Some of the parents spoke about their concern that the appearance of a child wearing a GoPro® in public would arouse suspicions:

People might think that's weird, even though people do that all the time with their cell phones and stuff, that's even more acceptable. I think people might be really self-conscious, because they're just not used to seeing that (a child wearing a GoPro®) and they wouldn't know what it was for.

Other parents felt as though the location of the child wearing the GoPro® was an important consideration. One mother stated, "I guess it depends on where you're at, you know? Like if you were in a grocery store or some store with people passing you in closer proximity, it might look a little weird." A father agreed, but thought that the child's age might also be a factor to consider:

On first impression, I guess that people might give him a second look. At (age) five or six or seven? I think there might be some judgment of an older kid. Not that you're supposed to or anything, but I just think, kind of naturally, some people would judge.

One mother answered the question with an alternate concern, expressing worry that if her son used the GoPro® to record his outing to certain public locations, it might encourage him to act in a socially unacceptable manner so that he could watch the experience later:

He might, you know, call a lot of attention to himself, like, at the grocery store. He and his brother, they like to push each other and wrestle in the grocery stores. They get in trouble for those things, so if they got a camera...trying to one up each other and make each other laugh and joke? You know? That sometimes...many times...gets out of hand.

Despite concerns about the social acceptability of their child wearing the GoPro® in certain public locations, each parent spoke about their wish to have POVM video of their child's experience in a school setting. One parent spoke about the advantage of knowing what approaches school personnel are using to meet the child's educational needs:

Wouldn't that be great if we could have that at school and see his point-of-view?! See how his teachers are handling things? That's the first thing I thought of was, 'this would be great to know why he's not focusing (in class).

Another parent expressed the same enthusiasm about POVM videos created by the child during his school day, but added an interest in knowing more about the child's peers:

Every parent wants to get to be a fly on that wall at their kid's school, you know?

Especially one that obviously has, you know, some special needs. I'd love to see how he

interacts with other kids...what their reactions are to him...to see if they think he's...you know, different or anything. I'd love to see that.

Key Theme: Well, I never noticed that!

We define this key theme to be new information that parents felt they gained about themselves and their children as a result of participating in the POVM intervention study. Parents reported gaining new insights about their child's behavior, sensitivities to environmental factors, and communication skills by viewing the child's POVM videos. One parent stated that they were "completely surprised" by the unique strategies that their child seemed to have developed on his own as a means of organizing and calming his thoughts. The parent shared an experience of watching a video that her son created using the head-mounted GoPro® camera to record his practicing a song on the piano:

We did get some details watching the video that I might not have got otherwise. There was one example of where he's playing the piano and he's singing the notes, to himself! I said, 'Oh, so you sing while you play to get the notes? Are they in your head and you're singing while you play?' And seeing his head move all over the place...he's looking everywhere but the music...He's not really reading the music, he's just playing! It was interesting because he would never say, 'I played the piano and I sing (the notes) while I play.'

The same parent reported discovering another behavior that she found interesting, in part because it is similar to a strategy that she also uses:

He talks to himself quite a bit! He's by himself, like, 'Hey, I'm going to go down the slide now...and hey, I'm going to ride down the street.' He was kind of laughing at himself because I think I said at one point, 'Boy, you talk

to yourself a lot!’ I do too! Him and I are SO much alike!

One parent found that sharing the POVM video helped her to better understand her child’s challenges with sharing details about daily events:

I think it’s kind of eye opening for them...to see themselves talking. I think it’s even harder for him to organize his thoughts, so...I think practicing that using the video...I would know more details, you know what I mean? He’s so busy trying to tell it like it was, but then he leaves out a bunch of details because he’s still trying to organize his thoughts enough to tell me about that activity...He doesn’t want to have to sit and think about it...making the video, he would just tell me more details.

Some parental insights came about more indirectly. During one session, a father learned that sound plays an important role in his son’s ability to communicate details:

I tried to mute the video some because I felt like he was distracted by the sound. But (my wife) pointed out that he might want to hear the sound because that kind of tells (my son) what he’s doing and he can explain it better. But then, pushing the pause thing...I just could see his mind working and I wish I would’ve done that earlier!

The same parent also shared the disbelief when he and his wife watched POVM video of their son playing with his younger sibling. This sibling interaction was something the parents had attempted to initiate many times with, what they assumed to be, limited success. The father said, “(My sons) were just playing together! (My wife) and I were just, almost in tears because we were just, you know, so happy that they were doing that!”

Discussion

The results of this study indicate that despite initial concerns about the processes and social acceptability of the intervention, parents found numerous benefits to utilizing the POVM

technique. Their primary concerns about the process included personal hesitations about being “qualified” to provide the POVM intervention and apprehension about their child recording video in public. Post-intervention interviews revealed that parents found that participation in the study led them to new insights about themselves and their child while engaging in an activity that was interesting for both of them. These findings support existing research about the challenges of balancing the benefits and responsibilities when utilizing parent-produced interventions for children with disabilities (McConachie & Diggle, 2007).

Findings of this study suggest that parents of children with ASD have conflicted feelings about providing structured, video based intervention for their child. For example, all of the parents spoke about the challenges of finding time for the intervention and “not knowing what to do” when they sat with their child to watch the videos. Some studies have cited convenience as a key advantages of parent-produced interventions (McConachie & Diggle, 2007); however, other investigations (e.g., Freuler et al., 2013) have highlighted the difficulties associated with initiating parent-produced interventions which often require intensive time. Therefore, researchers have called for intervention research to begin to assess parent and child outcomes (Karst & Van Hecke, 2012). Conversely, parent frustrations in the current study may not have been related to the intervention itself but rather the features required by the research design (i.e., researchers providing minimal instructions for parent/child interactions, setting up multiple cameras to record parent/child interactions, transferring data files for transcription).

Previous research about parent-produced interventions reports increases in parents’ confidence providing interventions when given autism-specific teaching strategies (Siller et al., 2013). Hutman et al. (2009) found that children with ASD demonstrated positive gains in their communication when parents were given tools to help structure their child’s play environment

and recognize opportunities to engage in communication. The current study's qualitative findings suggest that families who choose to implement parent-produced POVM intervention may benefit from intermittent professional guidance individualized to suit the families' unique circumstances. Tailored intervention strategies that would accompany the POVM intervention may include: choosing a suitable environment to watch the videos, coaching to recognizing child's attempts at communication, or suggesting approaches to pausing/rewinding videos.

Parents also reported feeling like they were gaining a sense of comfort in using the intervention as the intervention ended. One participant stated, we "were just getting used to (interacting with their child while watching the POVM videos)." In the larger intervention study, we employed a two-standard deviation band method to analyze data. A benefit of the two-standard deviation band method is the opportunity for researchers to determine statistical significance of an intervention in a short time. In fact, all participants in this study achieved statistically significant results within the first three intervention sessions, effectively ending their participation. While advantageous for researchers attempting to develop new approaches to intervention, the two-standard deviation band method of analysis appears to have prevented parents from gaining a sense of competence over time to fully explore and develop their own approaches to using the POVM technique.

Wearable cameras in public. The participants' nervousness about video recording in public is not unfounded; psychological research exists that suggests the very presence of a video camera can cause people to experience elevated levels of anxiety and self-awareness, resulting in changes to their behavior (MacIntyre & Gardner, 1994). A common debate resulting from these studies is whether the act of video recording an interaction changes the nature of that interaction (Cuff et al., 2008; Hoyle et al., 2014). Though there is no consensus answer to that theoretical

question, there is substantial guidance about the benefits of analyzing video to improve individual performance within the fields of education, medicine and therapeutic practice (Parry, 2010). Among ASD-related research, video modeling is listed as an evidence-based practice with wide-ranging applications (Kasari & Patterson, 2012; Reichow & Volkmar, 2010; Wong et al., 2015).

POVM as a parent-provided intervention. Families in this study reported satisfaction with the intervention, and such positive outcomes included learning new things about their child and discovering a mutually interesting, child-led activity. Research about parent-produced interventions supports these positive impressions. Green et al. (2010) reported that parent-produced interventions led to improvements in parents' understanding of their child's communication strengths and increased parents' sensitivity to social situations that might be more challenging for their child. Additional research addresses the transactional benefits associated with parent-produced interventions. A meta-analysis of parent-mediated interventions (Roberts & Kaiser, 2011) affirms additional findings from this study that suggest when parents participate in activities aimed at developing their child's social interaction skills, parents inevitably learn about their own interaction styles and make adjustments to better match their child's needs (e.g., decreasing rate of speech, developing joint attention). Such modifications to parent/child interactions take steps toward generalization and greater long-term benefits (Leffel & Suskind, 2013; Roberts & Kaiser, 2011). Although parents expressed varying levels of comfort with the technology used in the intervention, they nonetheless found the novelty of the activity beneficial. With more time and intervention opportunities, we may be better able to understand the transactional benefits of using a POVM with families of children with ASD.

Limitations

A commonly reported drawback of ASD-related research is limited generalizability.

The participants in this study, for example, were from the same area of the United States and share similar demographic characteristics. Based on the results of this study, incorporating greater diversity among the participants would correspond to greater diversity in implementation methodologies and a more robust understanding of this parent-produced POVM approach. Another limitation of this study is that parents were asked to report about their experiences after a relatively short duration of time. In the future, a more long-term assessment of the participants' experiences that incorporates pre- and post-intervention measures may prove to be informative.

Conclusion

Considering parents and caregivers to be vital components of a successful treatment program for children with ASD is an important consideration for treatment. Data from this study highlight the importance of considering parents' experiences as essential sources of information when designing and individualizing new approaches to intervention. Although further research is necessary to better understand potential variations and efficacy of this parent-produced POVM technique, each of participants in this study shared their appreciation for the increased time engaged in mutually enjoyable activity with their child. As one father said to summarize the experience of sitting next to his son to watch videos that his son recorded with the wearable camera: "The more I can see of him the better...That's pretty much for my whole life, you know?"

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Appendix A

CODING KEY FOR CONVERSATIONAL EXCHANGES

Exchange Response Code	Description	Examples
Conversational match (<i>M</i>)	Non-imitative response	“What did you do today?” “I played.”
	Without the parent’s use of additional sounds and/or gestures to prompt the child’s response	“Where is your brother?” “Went outside.”
	Independently answering “yes” or “no”	Do you want some juice?” “Yes.”
	Could be an inaccurate response, but still related to topic	“How was the dentist?” “Fun.”
	A non-verbal response, such as following a parent’s direction, nodding, etc.	“Come sit down.” (child sits down)
Conversational match with prompts (<i>MP</i>)	Repeated word or partial phrase from parent’s immediately previous conversational turn	“Are you tired?” (child shakes head “no”)
	Verbal imitation produced < 4 sec after parent’s question/statement	“Say, Mom I want a turn!” “Mom, I want a turn.”
	Response follows a parent’s use of any of the following to prompt:	
	Sounds	“What are you watching?” “Watching.”
	Incomplete sentence ‘fill in the blank’	“We played with /L/...” “Legos.” “On the swing, you went up and...” “Down.”
	Pointing	“Tonight for dinner you had...” “Spaghetti” “What is this?” (parent points to an item in the video) “Fire truck.”
	Gestures	“That building looks really...?” (parent stretches their arms away from their body) “Big.”
	Sign Language	“What did you do at the park?” (parent signs “slide”) “Slide.”
Response does not match (<i>DNM</i>)	Unintelligible response	“What do you want to do next?” (child verbalizes an unintelligible response)
	No response	“Hey, do you need some help?” (child appears to ignore question)
	Off-topic response, without context	“Where is your backpack?” “Safelite repair...Safelite replace!”
	Request for an item or activity that the child initiates on his/her own	“How was school?” “Could I have a cookie?”
	Statement initiating a new conversational topic	“Did you have fun with your friend?” “Look! It’s a dog!”

Appendix B

Informed Consent Form- Parent and Child Participants

Video Recording of Parent and Child Wearable Cameras and Verbal Interaction

Protocol #

INTRODUCTION

You are being asked to join a research study. You are being asked to take part in this study because of your stated interest in developing interventions for individual diagnosed with autism spectrum disorder. You do not have to participate in this research study. The main purpose of research is to create new knowledge for the benefit of future patients and society in general. Research studies may or may not benefit the people who participate.

Research is voluntary, and you may change your mind at any time. There will be no penalty to you if you decide not to participate, or if you start the study and decide to stop early. Either way, you can still get medical care and services at the University of Kansas Medical Center (KUMC).

This consent form explains what you have to do if you are in the study. It also describes the possible risks and benefits. Please read the form carefully and ask as many questions as you need to, before deciding about this research.

You can ask questions now or anytime during the study. The researchers will tell you if they receive any new information that might cause you to change your mind about participating.

This research study will take place at the University of Kansas Medical Center (KUMC) with Dr. Winnie Dunn as the researcher. About 5 people will be in the study at KUMC.

BACKGROUND

The use of video has proven to be an important technique in autism intervention. We are exploring how videos recorded by children wearing an action camera may improve verbal interaction. We will be observing the interactions between parents and their child as they watch a video that the child recorded of an outing earlier that day. Information from this study may provide valuable information that could guide future use of videos as a support for communication.

PURPOSE

By doing this study, researchers hope to learn about ways that video recorded by individuals wearing a small camera can benefit social interactions between children diagnosed with autism and their parents.

PROCEDURES

If your child is eligible and you decide to allow your child to participate in this study, the research team will work with you to schedule a time family to participate in a brief training regarding the use of the wearable camera for recording when your child will be engaged in a

favorite public activity (e.g., going to the park, walking through museum, etc.). For approximately 15-30 minutes, your child will record their experience using a GoPro camera mounted with a chest harness or clipped to a backpack strap.

After returning home from the event, you and your child will watch the video that your child made while you video record the interaction between you and your child. The only interactions that will be recorded are those between the child and parent.

Following the recorded interaction between you and your child watching the video together, you will complete a brief questionnaire about the interaction (e.g., *What did you think about the video? What changes, if any, did you notice about your child when you asked about things in the video? etc.*). The interactions between you and your child and the brief interview will last no more than 30 minutes. The research team will collect these recordings and the corresponding parent questionnaires at the end of each week. We anticipate your participation to last from four to six weeks.

RISKS

Child participants will be video recorded interacting with their parent. Videos generated for this study will be facially identifiable and someone viewing could recognize you in the video. We will maintain the anonymity of participant data by assigning a unique ID number for each participant. Only the research staff will have access to identifiable participant information. No transcriptions of the videos will include information that could be used to identify participants.

There may be other risks of the study that are not yet known.

NEW FINDINGS STATEMENT

You will be told about anything new that might change your decision to be in this study. You may be asked to sign a new consent form if this occurs.

BENEFITS

There are no direct benefits from participation in this study. Researchers hope that the information from this research study may be useful in understanding parent/child interactions when watching videos made by the child.

ALTERNATIVES

Participation in this study is voluntary. Deciding not to participate will have no effect on the care, services or education you or your child receives at the University of Kansas Medical Center.

COSTS

There is no cost for being in the study.

PAYMENT TO SUBJECTS

There is no payment for this study.

IN THE EVENT OF INJURY

If you have been harmed or had any other problem during this study, you should immediately contact Keenan Stump at 913-549-8282. A member of the research team will decide what type of treatment, if any, is best for you at that time.

INSTITUTIONAL DISCLAIMER STATEMENT

If you think you or your child has been harmed as a result of participating in research at the University of Kansas Medical Center (KUMC), you should contact the Director, Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160. Under certain conditions, Kansas state law or the Kansas Tort Claims Act may allow for payment to persons who are injured in research at KUMC.

CONFIDENTIALITY

The researchers will protect your and your child's information, as required by law. Absolute confidentiality cannot be guaranteed because persons outside the study team may need to look at your child's study records. The researchers may publish the results of the study. If they do, they will only discuss group results. Neither your nor your child's name will be used in any publication or presentation about the study.

Video recordings generated for this study will be labeled using a unique numeric ID and stored for fifteen years (per university policy) electronically on a secure KUMC network drive. After fifteen year, videos will be destroyed.

QUESTIONS

Before you sign this form, Dr. Winnie Dunn or Keenan Stump should answer all your questions. You can talk to the researchers if you have any more questions, suggestions, concerns or complaints after signing this form. If you have any questions about your rights as a research subject, or if you want to talk with someone who is not involved in the study, you may call the Human Subjects Committee at (913) 588-1240. You may also write the Human Subjects Committee at Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY

You may stop being in the study at any time. Your decision to stop will not prevent you or your child from getting treatment or services at KUMC. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

CONSENT

Dr. Winnie Dunn or a member of the research team has given you information about this research study. They have explained what will be done and how long it will take. They explained any inconvenience, discomfort or risks that may be experienced during this study.

By signing this form, you say that you freely and voluntarily consent for you and your child to participate in this research study. You have read the information and had your questions answered.

You will be given a signed copy of the consent form to keep for your records.

Print Participant's Name

Signature of Participant

Time

Date

Print Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

CHILD/ADOLESCENT ASSENT

I understand that I am being asked to participate in a research project that will help doctors understand how my parents and I talk to each other. The study may help doctors and therapists take better care of children and adults with autism.

If I want to be part of the research, I will need to help my parents and a therapist make a video of me and my family. My parents have given permission for me to be in this research. If I sign my name, I am saying that I want to be in the research. I know that I don't have to do it and that I can stop being in the research even if I signed my name. If I want to stop, all I have to do is tell my parents, the doctor, or any research team member.

Participant Signature

Age

Date

Appendix C
Comprehensive Examination I

Autism-Related Insurance Mandates: Implications for Evidence-Based Practice

Keenan C. Stump, M.S.

Comprehensive Examination I

Introduction

As of February 2014, 33 states have enacted autism insurance reform laws, with 10 additional states pursuing bills within their legislature (Autism Speaks, 2014). Among the states that have passed autism spectrum disorder (ASD)-specific legislation, trends are emerging that illustrate the positive and negative impact of these laws on the delivery of evidence-based services. Prior to passage of the first states' mandates in 2007, federal and state waiver systems provided the majority of services for individuals with an ASD, with public education and early intervention programs providing additional supports through The Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004) IDEA; (Kogan et al., 2008). Whether based on a physician-prescribed amount of additional services, published recommendations, or the belief that "more is always better," families frequently supplement school and waiver funded services to pay therapists privately to provide additional intervention (Dymond, Gilson, & Myran, 2007; Jarbrink, Fombonne, & Knapp, 2003). As more states require insurance companies to cover autism-related services, the mandate to provide evidence-based services will continue to intensify (Wong et al., 2013; Dymond, et al., 2007).

The term *evidence-based practice* (EBP) broadly describes a growing number of approaches that qualify as the integration of the best-researched evidence, professional judgment, patient values, and sustainability (National Autism Center, 2009). In autism-related services, comprehensive treatment models (CTMs) that have been individualized to address core challenges associated with an ASD (e.g., communication, behavior, socialization, etc.) are recognized in the literature as the framework for EBP (Odom, Collet-Klingenberg, Rogers, & Hatton, 2010; Rogers & Vismara, 2010; National Autism Center, 2009).

The literature defines CTMs as broad intervention practices administered intensively (frequently more than 20 hours per week) and over extended periods of time (National Research Center, 2001; Odom, Boyd, Hall, & Hume, 2010). Odom et al. (2010) further define CTMs as collections of “focused” interventions (i.e., techniques used to target specific skills, such as prompting, fading, discrete trial training, etc.) administered across multiple environments. Many times, CTMs are known by what Rogers & Vismara (2008) refer to as “brand” names to include the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH; Mesibov, et al., 2004), Social Communication Emotional Regulation and Transactional Support (SCERTS; Prizant, et al., 2006), and Pivotal Response Treatment (PRT; Koegel & Koegel, 2006). In their 2014 review of existing literature, Wong and colleagues created recommendations for EBP by analyzing evidence for both CTMs and focused treatments for ASDs. Analysis of these recommended EBPs yields common themes as critical aspects of successful implementation of EBP including: (1) the need for collaboration among family members and service providers, (2) the importance of providing continuous and coordinated care during times of developmental transition (e.g., early childhood programs to public school, adolescence to adulthood, etc.), and (3) the importance of delivering services within a number of contexts to encourage the generalization of skills to promote independence.

Of the states that mandate insurance coverage of ASD-related services, most support these three common features of EBP by authorizing multiple disciplines to provide services within varied service delivery systems, rather than endorsing any singular treatment approach. However, as legislation is developed to mandate reimbursement for ASD-related services, traditional healthcare reimbursement processes often provide the framework for coordination of service delivery and funding (e.g., deductibles, numbers of visits, in-network providers, etc.). In

an effort to better understand the complex interaction between delivering individualized and comprehensive services within the traditional features of commercial health insurance policies, this paper will focus on the ways in which the states' mandates have both supported and been barriers to the implementation of EBPs. We will examine positive changes to service delivery as a result of mandated coverage in the these key areas of collaboration, continuous care, and generalization. The paper will conclude by offering considerations for future mandated insurance coverage, as more research about EBPs emerges and states continue to create and revise their laws.

Collaboration

Collaboration among service providers and caregivers is an essential part of providing individualized, comprehensive interventions for people with an ASD. Collaboration allows those involved in the life of a person with an ASD the opportunity to share their knowledge, incorporating multiple perspectives to intervention practices (Swiezy, Stuart, & Korzekwa, 2008; Barnes and Turner, 2001; American Speech-Language-Hearing Association [ASHA], 1991). Although the description varies by discipline, collaboration commonly includes co-treatment, shared decision-making, and consultation (Kelly & Tincani, 2013; American Occupational Therapy Association [AOTA], 2008; ASHA, 1991). This team approach builds consistent service delivery from those providing interventions in multiple contexts, therefore increasing the likelihood of achieving successful outcomes (Iovannone, Dunlap, Huber, & Kincaid, 2003; Schreibman & Koegel, 1996;).

Coordinating and maintaining the levels of communication necessary for collaborative practices, however, can be challenging for caregivers, professionals, and individuals with ASDs (Parish, Thomas, Rose, Kilany, & McConville, 2012; Swiezy et al, 2008). Stokols and colleagues

(2008) described interpersonal, contextual, and organizational barriers to the collaborative process. The authors found that successful collaboration models are labor intensive, requiring leadership and planning to be exhibited by individuals who value the ideas of others. Perhaps as a result of such challenges, families frequently cite poor collaboration with and among service providers as a primary cause for concern (Howland et al., 2006; Koegel & Koegel, 1995; Little, Gearhart, Curry, & Kafka, 2003).

Despite these challenges, current legislation by states supports a trend toward improving interdisciplinary collaboration practices (e.g., Alaska, Michigan, Arkansas, etc.) (Alaska Stat. §21.42.397, 2012; Ark. Code Ann. §23-99-418, 2011; Mich. Comp. Laws §550.1461(e), 2011). The key component of these supportive mandates is that they do not specify the annual number of intervention sessions. With an increased number of sessions, there is a subsequent increase in opportunities for collaboration between providers funded by private insurance and other members of the intervention team. If considered in this regard, the legislation removes a barrier to collaboration and places the responsibility of successful collaborative EBP in the hands of the professionals and families.

States vary in their approach to mandating insurance coverage for therapy visits to individuals with an ASD. For example, Missouri, Alaska, and New Hampshire do not place limits on related services (i.e., speech and occupational therapy), but may limit the funding dedicated to behavioral therapies (i.e., applied behavior analysis [ABA]) (Alaska Stat. §21.42.397, 2012; Mo. Rev. Stat. §376.1224, 2010; N. H. Rev. Stat. Ann. §417-E:2, 2011). Comparatively, Iowa, Illinois, and South Carolina place yearly monetary limits on the number of covered services (IL Comp. Stat. ch. 215, § 5/356z.14 et seq., 2009; Iowa Code §514C.28, 2005; S.C. Code Ann. § 38-71-280, 2007). New Jersey's law allows insurance carriers to limit the

number of visits for services targeting ASD-related areas, while maintaining coverage for the same service type for an unrelated condition (i.e., visits to an occupational therapist for treatment of a broken ankle will not subtract from the total number of allowable visits related to ASD-related treatment (N.J. Rev. Stat. §17:48-6ii, §17:48A-7ff, §17:48E-35.33, §17B:26-2.1cc, §17B:27-46.1ii, §17B:27A-7.16, §17B:27A-19.20, §26:2J-4.34, §52:14-17.29p, & §52:14-17.46.6b, 2009).

In contrast, the wording of some of the first mandates (e.g., Texas, Florida, Arizona, etc.) reflected a traditional insurance practice of limiting the number of therapy sessions (Ariz. Rev. Stat. Ann. §20-826.04, §20-1057.11, §20-1402.03, §20-1404.03, 2009; Fla. Stat. Ann. §627.6686, 2008; Tex. Ins. Code Ann. §1355.015, 2007). As a result, parents and service providers are less likely to initiate collaborative meetings and co-treatments, believing that individual therapy is a better use of their allowable sessions (Hanft & Pilkington, 2000). Further, Meadows and colleagues (2011) listed a lack of reimbursement as a major reason for medical professionals' unwillingness to provide ongoing services.

Caregivers and service providers share the responsibility of initiating the levels of collaborative communication necessary to implement EBPs (Wong et al., 2014; Dymond, et al, 2007). By removing restrictions to service delivery, however, lawmakers have taken steps to support the collaborative practices of consultation and co-treatment. Such practices encourage coordinated and continuous care (Knowles, 2009; Woods, Wilcox, Friedman, & Murch, 2011) and have the ability to empower caregivers in the process.

Continuity of Care at Key Points of Transition

Across the lifespan of an individual with a disability, there are key points widely regarded as important times of transition (IDEA, 2004). Maintaining continuity of services

during the transition from Part C to Part B of IDEA, for example, is important due in part to the shift in therapeutic focus from preschool to school-aged services (Hanson et al., 2000).

Although individual experiences vary, this transition between service delivery systems is a relatively established process, focused on the design and implementation of individualized programs within school systems (Branson & Bingham, 2009).

In contrast, an area of growing importance and comparatively less research is the transition from adolescence to adulthood. Hendricks and Wehman (2009) defined this transition to include education, employment, and community integration. Their review of existing literature confirmed the importance of families and professionals working together to provide appropriate skills and supports to encourage an individual's success. Although a number of existing state mandates allow insurance companies to reduce services when a child reaches adolescence, more recently mandates have recognized the importance of coverage for autism-related services to age 21 (e.g., Alaska, New Jersey, Louisiana, etc.) (Alaska Stat. §21.42.397, 2012; La. Rev. Stat. Ann. §22:1050, 2012; N.J. Rev. Stat. §17:48-6ii, §17:48A-7ff, §17:48E-35.33, §17B:26-2.1cc, §17B:27-46.1ii, §17B:27A-7.16, §17B:27A-19.20, §26:2J-4.34, §52:14-17.29p, & §52:14-17.46.6b, 2009;).

During adolescence, the period of growth between the ages of 10 and 19, individuals undergo important physical and cognitive changes (Sawyer et al., 2012). Adolescents are expected to develop self-advocacy, form and maintain relationships, and create a more mature personal identity and sense of purpose (Jenkins, 2007). For children diagnosed with an ASD, these aspects of typical adolescent development can be challenging because adolescents with an ASD develop relationships and a personal identity differently from their peers (Shea & Mesibov, 2005). In states with recently created legislation, such as Alaska and Vermont, lawmakers have

taken steps to encourage the continuity of care during this important developmental period (Alaska Stat. §21.42.397, 2012; 2012 Vt. Acts, Act 158, 2012).

Somewhat paradoxically, other state mandates include age restrictions on reimbursable services by eliminating or diminishing coverage for individuals prior to their adolescent years. Kentucky's mandate, for example, requires insurance companies to provide a maximum annual benefit of \$50,000 until the age of seven, with a \$1000 maximum *monthly* benefit between the ages of seven and 21 (Ky. Rev. Stat. §304.17A-142, 2010). Other states cease to mandate coverage entirely once a child reaches a certain age. In Texas, mandated coverage for individuals with ASD is discontinued at nine years of age (Tex. Ins. Code Ann. §1355.015, 2007).

Such examples of coverage limitations overlook the growing body of literature promoting the importance of supporting individuals with ASDs during adolescence and the transition to adulthood (Reichow & Volkmar, 2010; Roux et al., 2013; Wehman et al., 2013;). Much like their previous transition from EI to school-based special education services, individuals with ASDs who are entering adulthood experience changes to the programs, location, and personnel involved in service delivery (Branson & Bingham, 2009; Rous, Hallam, Harbin, McCormick, & Young, 2007). States that mandate coverage to age 21 allow for individuals with ASDs and their families to work with privately funded service providers to navigate a successful transition to higher education, employment, and independent living options.

Generalization

The culminating focal point of evidence-based intervention is generalization. Much of the literature defines generalization as an individual's ability to employ skills across settings and

people (Osnes & Lieblein, 2003; Koegel & Koegel, 1990). Although this definition accurately addresses the importance of providing services across a variety of environments, this paper discusses generalization as a term reflecting greater issues of sustainability and independence. As people with a diagnosis of ASD enter adulthood, the expectation becomes that individuals live and work independently or with appropriate support (Hume, Loftin, & Lantz, 2009). In this regard, generalization is considered a definitive product of service delivery, a practical application of interests and abilities resulting in self-sufficiency and empowerment (Iovannone, et al, 2003).

Evidence suggests that intervention services promote an individual's ability to generalize when they are provided within natural settings and routines and include interactions with numerous people (Klin Volkmar, & Sparrow, 2000; NRC, 2001; Simpson, 2005). Hume, Loftin, and Lantz (2009) concluded that intervention approaches targeting independent functioning (e.g., self-monitoring, independent work systems, video modeling, etc.) promoted the acquisition of skills that lead to independence. The inclusion of family, peers, and others from the individual's community in the intervention process is vital to generalization, and considered a necessary part of providing effective services (Benson & Kersch, 2011; NRC, 2001; Shreibman & Koegel, 2005; Smith et.al, 2010).

Many states' mandates have required that services (e.g., speech, occupational, and behavioral therapies, etc.) be prescribed by physicians as "medically necessary." As a result, mandates in states such as Nevada and Illinois allow insurance reimbursement to cover services prescribed by a physician and rendered at clinical facilities on an outpatient basis (IL Comp. Stat. ch. 215, § 5/356z.14 et seq., 2009; Nev. Rev. Stat. §689A.0435, 2011). Studying the effects of mandated insurance coverage on location of service delivery, Stein et al. (2012) found a

decreased use of community-based services and a corresponding increase in the use of outpatient services. Such facility-based services do not align with the predominant body of literature indicating that a family's direct involvement in intervention results in more successful outcomes (Benson & Kersch, 2011; Shreibman & Koegel, 2005; Smith et.al, 2010). Additionally, research suggests that providing intervention services outside of the natural context (e.g., a self-contained environment, clinical setting, etc.) decreases the likelihood that a treatment program will remain informed enough to meet the ever-changing and varied goals of an individual and their family (Freedman & Boyer, 2000; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999).

By including language that specifically addresses the need for services to be *evidence-based* (e.g., Arkansas, Vermont, etc.), most mandates encourage generalization, albeit indirectly (Ark. Code Ann. §23-99-418, 2011; 2012 Vt. Acts, Act 158, 2012). These more recent versions of legislation provide financial support for intervention services delivered within naturally-occurring routines and community-based environments, which support generalization (Greenspan & Wieder, 1997; Mahoney & Perales, 2005; Wieder & Greenspan, 2004). Similarly, Test and Grossi (2011) found that life skills taught in natural environments are a strong predictor of post-graduate success. The authors included such examples as teaching about shopping (e.g., pricing items, using a debit card, etc.) and explaining the differences in social interaction between the individual and their employer versus their peers. The Ohio Center for Autism and Low Incidence (OCALI2012) reported that skills are more likely to generalize during authentic work experience. The authors discussed the importance of initially providing supports during experiences such as community volunteer events, internships and mentorships, and job shadowing to develop independence.

As research and interventions emerge regarding generalization, lawmakers are creating and revising laws to reflect a combination of EBPs from the domain of autism research and emerging data about the efficacy of prior legislation from other states. As a result, positive changes to the delivery of EBPs within the field of autism-related services are emerging. By continuing to embrace these changes, within existing legislation and funding practices, lawmakers, families, and professionals are collaborating to create positive outcomes for individuals with ASDs (Dymond, et al, 2007).

Considerations for Future Coverage

States have been improving legislation that reflects the relationship between evidence-based intervention and state-mandated insurance coverage of ASDs. Although adequate research about evidence-based service delivery exists to provide general considerations for future legislation, there will continue to be a need for ongoing research to examine and compare the effectiveness of individual mandates. Building upon current evidence and emerging studies synthesizing the effectiveness of evidence-based intervention, several recommendations are relevant for both policy makers and practitioners:

1. *Promote and implement evidence-based practice.* Several researchers have promoted ongoing opportunities for families' and providers' skill development (Turnbull et al., 2001; Simpson, 2003). A number of states have promoted the creation and dissemination of free resources about evidence-based practices to families, educators, and service providers. In an effort to encourage consumer education about EBPs and link consumers to community resources, mandates in states such as Missouri and California include funding for educational materials and training opportunities (Cal. Health & Safety Code §1374.73, 2011; Mo. Rev.

Stat. §376.1224, 2010). The Missouri Autism Guidelines Initiative (MAGI) is an example of a state-funded committee formed to develop and publicize materials about EBPs (MAGI, 2010). As lawmakers continue to create and revise legislation, they must also consider innovative and effective ways to keep the public informed (e.g., use of social media, Podcasts, webinars, etc.).

2. *Utilize models from states with effective relationships between Medicaid waiver programs and private insurance.* States are primarily responsible for the administrative structure of Medicaid. In North Carolina, Medicaid is used to fund programs such as Community Care of North Carolina (CCNC). CCNC focuses on developing networks of health care providers from both governmental agencies and private industry to coordinate services and improve individuals' access to (Ricketts et al., 2004). Dewalt and colleagues (2005) found that by supporting the infrastructure for such collaborative measures, North Carolina's Medicaid system has led to improved quality of care and decreased health care costs. North Carolina's creative strategies provide examples of ways that Medicaid's role may be expanded to improve the quality and continuity of care. It is important to note that a 2013 letter from the Interagency Autism Coordinating Committee (IACC) to the Secretary of Health and Human Services recommends fundamental treatment standards for both publically funded agencies and private industry (IACC, 2013). Although this does not directly impact the funding for services, it is indicative of a greater need to create alignment between public and private funding sources.

3. *Examine consumer satisfaction among the various approaches to mandated benefits.* Future state-level research must examine the variables that affect consumer experiences and evaluate the quality of existing services for individuals with ASD (Dymond, et al, 2007). Involving consumers in the evaluation process provides guidance for future legislative action and insurance company procedures, while increasing the consumers' sense of inclusion in the decision-making process (Turnbull, Wilcox, & Stowe, 2002). Furthermore, such data may be shared among states as a means of effectively translating and improving innovation (Dewalt, Oberlander, Carey, & Roper, 2005). By including funding for groups specifically assigned to this task (e.g., state agencies that coordinate funding for services, members of the insurance regulation committee, university researchers, etc.), the process of authorizing insurance coverage is informed by those who utilize autism-related services.
4. *Close loopholes that restrict coverage.* States have regulatory commissions that are specifically devoted to protecting the interests of their state's insurance consumers. Questions continue to arise, however, around which state's laws apply in cases where the consumers are located in a state other than the one where their policy was issued (National Conference of State Legislatures [NCSL], 2013). From a consumer's standpoint, companies with group policies run into challenges when portions of their workforces are located in states *other* than the ones where the initial group policies were issued. Similarly, insurance companies

become confused about achieving compliance for consumers that may share a company policy, but are located in different states. Some believe that this uncertainty has increased the attractiveness for interstate business to pursue private insurance under the Employee Retirement Income Security Act (ERISA), undermining the states' goals of protecting their residents with mandated coverage (NCSL, 2013).

5. *Increase access to highly qualified education for future providers.* Evidence suggests that higher education programs devoted to ASD intervention and coaching with ongoing feedback models provide effective training for service providers (Joyce & Showers, 2002; Simpson, et al 2003). Additional studies from the fields of education and medicine discuss the importance of providing an education about ASDs to people who will offer services (Loiacono & Allen, 2008; Swiezy, et al, 2008). Creating educational opportunities for future providers addresses consumer concerns regarding the lack of access to providers with ASD-related experience within their insurance companies' networks (Dymond, Gilson, & Myran, 2007). States should consider subsidizing such features in future legislation as part of preparation and certification practices.

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Appendix D

Comprehensive Examination II

Social Interaction and Autism: Autobiographical Literature as Evidence

Keenan C. Stump, M.S.

Comprehensive Examination II

Abstract

This study examined how the personal experiences of individuals with Autism Spectrum Disorders (ASDs) learning about social interaction compare to recommendations derived from a recent systematic review. The findings compliment an evolving body of literature recognizing the importance of including the perspectives of individuals with ASDs as a necessary companion to recommendations derived from traditional research. A qualitative framework (i.e., thematic analysis) was used to examine selected autobiographical literature. Although the systematic review offers descriptions of focused social interventions, the findings of this study indicate that the systematic review does little to address the complexities that affect an individual's social experiences. This was the first study to compare a systematic review's recommendations about social intervention with the suggestions from individuals with ASD who have chosen to write about their experiences. Recommendations based upon these findings are discussed, particularly for service providers and researchers.

Keywords: Autism spectrum disorders, Social cognition and social behavior, Interventions – psychosocial/behavioral, Qualitative research, Sensory impairments, School-age children, Adults, Adolescents

Introduction

While challenging for many, social interaction is an area commonly addressed by caregivers and service providers involved in the lives of people diagnosed with an autism spectrum disorder (ASD) (Grandin & Barron, 2005; Klin et. al, 2007; Reichow & Volkmar, 2010). The use of social communication and interaction are key features used to differentiate ASDs from other developmental disabilities (American Psychiatric Association, 2013). Given the importance of social communication, scholars have designed and evaluated many ways to facilitate the development of social skills for individuals with ASDs. Families, researchers, and service providers have created a variety of promising approaches that target social skills, with a number of these practices considered “evidence-based” in comprehensive reviews of the literature and systematic analyses (e.g., social skills groups, peer-moderated programs, video modeling, etc.) (National Autism Center, 2009; Wong et. al, 2014).

In addition to the substantial amount of published work from researchers, individuals diagnosed with autism have produced books, blogs, and podcasts to discuss their experiences in formats more accessible to general society. Among the range of topics that these works address, challenges associated social interaction has emerged as a common theme. Popular authors such as Temple Grandin (*Thinking In Pictures*), Daniel Tammet (*Born On A Blue Day*), and John Elder Robison (*Look Me In The Eye*) have written best-selling books about their lives, offering insight into the different ways that they perceive their minds learn about and maintain social relationships. Researchers and providers do not typically view these works of personal experience as being of equal importance to published research. Despite this disparity in consideration of research over public press works, many times the focus of researchers studying social skill development is on the same challenges that authors with ASDs choose to write about.

Therefore, the information in autobiographies seems worthy of consideration as we design research for the future.

Evidence as a Guide to Practice

There are standards for both quantitative and qualitative methodologies used to create the scientific evidence to guide practice. Systematic reviews and meta-analyses are used to summarize existing evidence to provide service providers the opportunity to choose proven interventions as part of the intervention planning process (Higgins & Green, 2005).

Organizations such as The National Professional Development Center on Autism Spectrum Disorders (NPDC) have produced reviews of literature to endorse specific evidence-based practices for use by ASD service providers. In their published reports, the authors discuss challenges associated with evaluating the literature, such as defining practice and grouping focused treatments into categories of targeted skills (e.g., academic, communication, self-regulation, etc.) (Odom et. al, 2010; Wong et. al, 2014). Their most recent report (2014) endorses practices for use in school settings to improve skills in areas such as behavior, academics, and social interaction.

The methods used in studies included in the NPDC's review (e.g., randomized control designs, measures of reliability and effect size, etc.) reflect the strength and rigor of quantitative research. However, such a focus on the numerical measurement of outcomes may not allow for interventions to be situated among the multiple contexts where social interaction challenges arise. For example, using a performance-based tool to tally the number of times a child initiates a turn during game play may result in greater measurement reliability, but the use of a contrived environment creates doubts about validity and generalization (Bellini, Peters, Benner, & Hopf, 2007).

Portney and Watkins (2008) explain that “quantitative methodology is linked to the philosophy of logical positivism, in which human experience is assumed to be limited to logical and controlled relationships between specific measurable variables” (p. 306). This explanation highlights limitations of quantitative measurement. Spontaneous social interactions are rarely consistent enough for reliable measurement (Chevallier et. al, 2012) and contain numerous variables (e.g., motivation to communicate, understanding of social signals, situational context, etc.) which are critical to the interaction.

Published research that uses qualitative methodology provides an additional source of information to guide practice. Qualitative studies employ observation and participant reporting techniques to produce descriptive accounts of individual experiences. These studies describe complexities that prove difficult to capture in quantitative research design (Parkinson & Drislane, 2011). Qualitative findings reveal the perceived effects of social intervention practices, such as parental satisfaction with an intervention process (Barnhill et. al, 2002; Cridland et. al, 2014), participants’ impressions (Griffith et. al, 2012; Minne & Segmund-Clíkeman, 2011), and the experiences of peers employed as part of a study (Harper, Symon, & Frea, 2008). With such variety among individualized approaches, it is challenging to complete a comprehensive synthesis of qualitative research surrounding the construct of social skills (Matson, Matson, & Rivet, 2007). Though the outcomes of such qualitative studies serve to remind service providers about the benefits of person-centered care and collaboration, challenges for determining generalization effectiveness and fidelity remain (Bellini, Peters, Benner, & Hopf, 2007).

The difficulties with conducting autism related-research contribute to the gap between research and practice (Dingfelder & Mandell, 2011; Lord et al., 2005). Smith et al. (2007) reported that despite the best efforts of researchers to synthesize, summarize, and disseminate

EBPs, there is limited guidance for implementing recommended practices in the community. Smith and colleagues' findings become increasingly apparent when the target outcomes involve dynamic social interactions that are both person-centered and context-dependent (Jones & Carr, 2004).

Autobiographical texts from individuals with ASDs are another descriptive source of personal experiences. Authors' approaches to creating their stories are diverse, reflecting the diversity of the authors themselves. Just as with any autobiography, authors with ASDs tell about their experiences in the form of past conversations, personal opinions, and observations of others during everyday life (Andrews, Squire, & Tamboukou, 2013). An existing bond among these wide-ranging and individualized stories about life with an ASD is the number of commonly discussed topics, including challenges to learning about social interaction.

Although popular autobiographical literature does not adhere to universally-accepted structures, the fields of social science, psychology, and medicine continue to develop personal narratives as an evidence-based approach to sharing insights between service providers and their consumers (Charon, 2001; Holmgren et. al, 2011). In their report to the Journal of American Medical Association (JAMA) encouraging patient narratives, Meisel and Karlawish (2011) found that narratives (e.g., storytelling, testimonials, and entertainment) led patients to feel that their input was valued. In addition to the patients reported benefits, Meisel and Karlawish (2011) reported that service providers felt a greater connection to their patients' experiences after hearing the patient narratives.

In a larger sense, Hinyard and Kreuter (2006) documented that the use of specifically autobiographical literature improves the general public's understanding of a topic, primarily due to the public's ability to identify with the authors' human experiences. The findings from the

studies above suggest that considering popular autobiographical literature from people with ASDs as personal narratives yields valuable insight for those providing social interventions.

Challenges to Popular Literature as Evidence

When considering popular autobiographical literature as a potential source of evidence for practice, it is important to understand potential reasons for excluding this information. Autobiographical works, by definition, are firsthand accounts that provide insight into personal experiences. Much like validity challenges that accompany the quantitative and qualitative studies of ASD limited to single-case and small group designs, autobiographical texts represent an individual sample. Such single-person accounts of experiences may not represent others' experiences, are not subject to peer review, and may prove difficult to replicate. As such, autobiographical authors may discuss self-support strategies and opinions that may not be applicable to the greater population of individuals with ASDs.

Another challenge to considering popular autobiographical literature as evidence relates to publishing industry practices. Generally, a primary goal of popular literature is wide distribution, not scientific advancement. These narratives, with their lack of methodological rigor and peer review, create doubt about content validity among scholars and service providers (Portney & Watkins, 2008). The concern is a fair one; publishers frequently assign co-authors, editors, and marketing teams to each of the projects they agree to fund. As a result, others revise the primary authors' works to provide a structure and style that potentially changes the form and content of the message created by the author (Atkinson, 2009). In some cases, revision teams invite a sympathetic experience from the reader, rather than reflect the objectivity of a social scientist (Atkinson, 2009).

Despite such concerns about practices within the publishing industry, information from the personal accounts of authors diagnosed with an ASD contain meaningful information for those involved in the lives of people on the spectrum. By applying a systematic and research-based approach to analyzing such autobiographies, researchers augment our understanding of social interaction interventions derived from quantitative and qualitative methods to better understand living with an ASD. A primary goal of this paper is to analyze popular autobiographical literature for themes related to learning about social interaction, and compare the findings to recommendations from a recent systematic review.

Research Design

A qualitative framework (i.e., thematic analysis) was used to analyze the autobiographical literature included in this paper. Thematic analysis allows for themes to emerge from peoples' reported experiences, but is not limited by the prescribed boundaries associated with similar methods of qualitative research (Braun & Clark, 2006). As examples, grounded theory, interpretive phenomenological analysis (IPA), and discourse analysis are qualitative methods with detailed guidelines for controlled data collection and analysis (Smith and Osborn, 2003). Thematic analysis provides the structure of a guided decision-making process and requires transparency, yet allows researchers the flexibility to draw conclusions from varied written sources (e.g., comedic experiences, instructional writing, introspective essays, etc.) (Braun & Clark, 2006). Since each of the five literary works included in this study were generated by different authors with inherently unique writing styles, the thematic analysis framework is appropriate to use to explore similarities and differences across each of the texts. To establish social validity and ensure that conclusions were relevant and respectful of personal

experiences, we contacted three self-advocates (i.e., people who have autism) to recommend autobiographical literature for analysis.

In order to compare the conclusions from the autobiographical literature with recommendations from published research, we selected a systematic review created by The National Professional Development Center on Autism Spectrum Disorders (Wong et. al, 2014). In addition to being the most recent report at this time, the authors took care to compare their findings to similar systematic reviews published in recent years (e.g., National Autism Center [2009] and NPDC's previous report [2010]). The use of systematic reviews and meta-analyses to summarize existing evidence affords service providers the opportunity to choose interventions as part of a decision-making process (Higgins & Green, 2005).

Methods

Five books by six different authors (one book contains passages written by two different authors to provide perspective) were selected for this study. Selection was based upon the recommendations of three adults with diagnoses of autism, who also identify themselves as instructors, authors, and self-advocates. We asked each of these individuals by email to recommend a list of autobiographical literature from authors diagnosed with autism, which they felt depicted accurate and respectful experiences of living with a diagnosis. Each of the three recommended the work of Temple Grandin (i.e., *The Unwritten Rules of Social Relationships*) and John Elder Robison's book, *Look Me In The Eye*.

In addition to these two agreed upon texts, we also included books written by each of the participants. The inclusion of the participants' autobiographical works as a data source is consistent with the principles of a thematic analysis and highlights the study's goal of

respectfully exploring the authors' experiences. The participants also agreed to review drafts of this study as a means of member checking.

Analytical approach

In accordance with the recommended approaches associated with thematic analysis, we collected data by tagging the pages of each of the books for every instance where the author chose to discuss their experiences learning about social interaction. These page tags were subsequently revisited and coded by topic, leading to the emergence of more organized themes.

Findings

The thematic analysis revealed four key themes addressing the authors' views on social interaction and intervention; 1.) The effects of personal sensory preferences on social interaction; 2.) The importance of choosing friends/peers; 3.) A recognition of parents/family as the principal influences on social development, and; 4.) The challenges related to social skills training. Consistent with a traditionally qualitative presentation, these four themes are presented below with data to support discussion points (Braun & Clark, 2006).

The Effect of Sensory Preferences

There is a substantial body of research exploring the ways that people with ASDs' sensory systems affect their interaction with the world (Baranek, David, Poe, Stone & Watson, 2006; Ben-Sasson et al., 2009; Ermer & Dunn, 1998; Watling, Deitz, & White, 2001; Tomchek & Dunn, 2007). While researchers have documented the relevance of sensory input as a predictor of academic success (Brown & Dunn, 2010) and behavioral compliance (Heflin & Alberto, 2001), we found that the autobiographical authors commonly discussed addressing personal sensory features as a necessary precursor to any social interaction. Zosia Zaks (2006) uniquely describes how she views her sensory system:

My senses seem to work on a quota system. I only have a set amount of energy or capacity to deal with incoming sensory information. I refer to this as my finite number of Sensory Processing Units. If most of my Sensory Processing Units are dealing with one type of input, fewer units are available for processing other types of input. (p. 8)

Similarly, John Elder Robison (2007) wrote, “To this day, when I speak, I find visual input to be distracting. When I was younger, if I saw something interesting I might begin to watch it and stop speaking entirely” (p. 3). It is worth noting that while these two examples describe different aspects of communication (i.e., Zaks refers to “input,” whereas Elder Robison discusses “speaking”), they both demonstrate the link between socialization and their sensory systems.

Each of the authors discussed the feelings of stress and anxiety caused by sensory-related challenges as barriers to interacting with others. Barron (2005) spoke about his aversion to interacting with classmates during social opportunities at lunchtime:

The noise and commotion were taxing to my senses. Thirty kids in an enclosed room was one thing, but ten times as many in a wide open echo-y space or room was overwhelming because I felt naked, exposed, and on display—even if no attention was on me. (p. 143)

Grandin (2005) discussed the impact of sensory-based anxiety on intervention practices, writing that until such issues “are addressed and alleviated, forget trying to teach more advanced aspects of behavior and sociability” (p. 181). Collectively, the autobiographical authors report that their sensory systems directly affect their social interactions.

Peers

All of the authors wrote about the importance of friendship as a critical feature of their social development. A key component of each of their friendships was the level of comfort that existed between the authors and the other person, a result of having shared interests. One author

described frustration during attempts to practice learned socialization techniques with people whom he did not share common interests, saying, “My efforts to placate the rest of the campus by pretending to be ‘normal’ resulted in pleasing virtually nobody while making me just as miserable and angry as I’d been for much of my life” (Saperstein, 2010, p. 94). Saperstein’s statement underscores other authors’ beliefs that common interests form the basis for successful friendships. John Elder Robison (2007) states:

As a young adult, I was lucky to discover and join the world of musicians and soundmen and special-effects people. People in those lines of work expected to deal with eccentric people. I was smart, I was capable, and I was creative, and for them that was good enough. (p. 211)

Grandin (2005) directly addresses the importance of providing people an opportunity to choose their friends to cultivate friendships, rather than being selected out of convenience:

True friendships are built on shared interests, or shared ideas, or shared principles that you both hold meaningful; Just being the same age, or the same sex, or in the same class or going to the same after-school activity doesn’t make a person a friend. (p. 417)

Zosia Zaks (2006) expanded upon the benefits of choosing a friend with similar interests by highlighting that friends with similar interests are more likely to participate in activities together:

Unlike social skills training, which is abstract and practiced only periodically, a friend is there during live action and understands life as it is. You may do eye contact perfectly in a social skills session where you know what the therapist expects, but while hanging out on the football field you may not be able to maintain proper eye contact. A friend can prompt you naturally: “Don’t forget to look at Sally this time when you ask her out for hot chocolate after the game!” (p. 309)

Importance of Parents and Family

Almost all of the authors chose to write about their parents as their most important and influential sources for understanding social interaction. Some authors credit the sense of safety they felt with their parents as providing the biggest benefits when discussing social challenges. Saperstein (2010) writes:

After we moved to California when I was sixteen, and I had settled into a new school, I spent many evenings in our California living room—sometimes until 1:00 or 2:00 a.m.—with one or both parents. They would often spend several hours trying every way they knew to explain the most basic concepts of how relationships worked. (p. 152)

This “parents as interventionists” idea is echoed by Stephen Shore (2005): “...given enough intensive time with a loving and caring person, such as the mother, the person on the autism spectrum can become a master at reading these (social) cues from that person (p. 83).

The authors also discussed their gratitude for their parents’ devotion and determination during stages of social development. Sean Barron (2005):

Over time—and thanks largely to my parents’ patience—I started developing a sense of critical judgment. It took years of listening, absorbing, watching and asking questions to lose my naiveté and to develop some insight into human nature. The process was slow and difficult, but my parents continued to guide. (p. 155)

Many of the authors cited their parents as the primary reason for their ultimate social successes and for providing them with the tools to educate others about the different ways that they perceive the social world. Zaks (2006) wrote, “Family members are the people who love us

the most. They are therefore the most likely to work with us in changing negative stereotypes and misconceptions about autistic people (p. 334).’

Recognizing the importance of parental influence in social development highlights the overarching role of the family in facilitating interpersonal relationships. Perhaps a more fundamentally important feature of family members teaching about social skills is the person’s belief that someone is sincerely invested in their ultimate success in life and will provide whatever supports are necessary to help the person achieve success. Sean Barron (2005) said of his parents, “They never gave up on me, and as a result, I didn’t give up on myself (p. 156).”

The Challenge of Social Skills Training

Based upon their personal experiences, the autobiographical authors discussed approaches they believe are successful to learning about social interaction. For example, the authors addressed the value of teaching about different types of person-to-person relationships (e.g., close versus casual friends, romantic relationships, community interactions, etc.) as an important conceptual precursor for learning about the act of socializing. Zosia Zaks (2006) explains that more direct explanation about these different types of interaction is an important, yet frequently overlooked, first step to understanding social relationships:

Since the very nature of friendship involves social exchange between at least two people, understanding concepts of friendship can be like trying to figure out life on an alien planet in a distant galaxy. Though ultimately you may choose to avoid most forms of social contact, having certain information about friendship will help you make sure that being alone is a true choice rather than a default option. (p. 305 - 306)

Similarly, Sean Barron (2005) wrote about the challenges of understanding different types of relationships during the years from grade school through high school. He discusses misunderstanding the differences of interacting with teachers versus fellow students, for example, as having an “effect of further widening the social gap between me and everyone else in my grade” (p. 137).

In addition to writing about a need for more direct teaching about *types* of friendship, the authors shared viewpoints about being taught social techniques. In summarizing his overall experience with social skills training, Saperstein (2010) concluded that “survival among the neurotypicals requires relentless compromise, overanalyzing the situation, and making life just a little more complicated in order to solve the simplest problems” (p.184). Based upon her learning experiences, Grandin (2005) suggests that service providers should consider teaching more about the distinct differences between what she refers to as *social functioning skills* (e.g., turn-taking, offering/returning common greetings, sharing, etc.) and *emotional relatedness* (e.g., considering others’ views, engaging in relationships, understanding personal feelings, etc.):

The first (social functioning) is a way of *acting*; the second (emotional relatedness) is a way of *feeling*. They are very different from one another, yet seem to be treated as the same within many of the popular social skills training programs that are developed for people with ASD. They also seem to be lumped together whenever conversation turns to “social skills.” (p. 89)

Saperstein (2010) reinforces Grandin’s belief in the value of teaching ways to socially “function” as sets of commonly accepted interaction skills: “Like a Microsoft Word program, I have stored separate files for funerals, weddings, job interviews, first dates, etc. These files may be accessed at a moment’s notice and compensate for my deficiencies with generalization” (p.

36). John Elder Robison (2007) further strengthens the case for this teaching approach saying, “the only real difference is that I have learned what people expect in common social situations. So I can act more normal and there’s less chance I’ll offend anyone” (p. 11).

In addition to offering their views about learning to socialize expressively, the authors frequently address the challenges of learning to interpret others. As mentioned above, Grandin (2005) uses the term “emotional relatedness” to describe “expressions of affection, outward actions that mirror inner feelings and emotions, consideration of others’ points of view” (p. 91). Zaks (2006) describes a fascination about how people that are not on the spectrum “are somehow able to tell what another person wants to communicate by looking at posture, facial expressions, and other subtle gestures” (p. 225). Stephen Shore (2003) describes his experiences:

Not only do I have to decode the words on the verbal channel, I also have to deal with the non-verbal channel consisting of body language, facial expressions, and tone of voice. To further confuse things, what is actually being said maybe different from what is implied by vocal inflections and other components of the nonverbal channel. In other words, having to read between the lines confuses things. (p. 121)

The authors agree that learning about social interaction is an equally complex and important process. They frequently described their experiences and offer direct suggestions to improve intervention practices.

Discussion

The primary research question asked about how the personal experiences of individuals with ASDs learning about social interaction compare to recommendations derived from published research. A broader goal of this paper is to contribute toward the creation of more

person-centered and strengths-based practices within the field of autism intervention (Myles, 2013). This study complements an evolving body of literature recognizing the importance of including the perspectives of individuals with ASDs as a necessary companion to recommendations derived from traditional research (Chen, Bundy, Cordier, & Einfeld, 2014; Robledo, Donnellan, & Strandt-Conroy, 2012). More specifically, these findings may inform intervention practices related to social interaction by comparing the most recently recommended EBPs with the lived experiences of individuals on the spectrum.

Based upon the findings of this study, there are differences between some of the NPDC's recommended interventions targeting social interaction and suggestions from authors with ASDs. The NPDC's report offers descriptions of focused social interventions and linkages to the studies that met criteria for inclusion in the systematic review, however it does little to address the complexities that affect an individual's experiences along the continuum of social development. Peer-Mediated Instruction and Intervention (PMII), Social Skills Training (SST), and Antecedent-Based Intervention (ABI) are examples of practices proven effective by traditional controlled research studies, but these may not fully address the features of social interaction highlighted by the authors with autism in their autobiographical accounts.

An example of this imbalance exists in the selection of intervention partners/peers. Each of the autobiographical authors discuss the peers who have provided assistance and friendship at various times during their educational and professional lives. One subtle, yet critical, difference between the authors' experiences and the recommended PMII techniques (as described in studies selected for the systematic review) is that the autobiographers valued peers of their choosing. In contrast, an examination of the fifteen studies included to qualify PMII as an EBP reveals that peers were generally selected by researchers using methods other than consideration of the

participants' preferences (e.g., selected peers were enrolled in the same class, assigned by classroom teachers, chosen randomly, etc.).

Social Skills Training (SST), another example of an NPDC recommended approach, also appears to lack alignment with the experiences of the autobiographical authors. The report describes SST as either group or individual “instruction on basic concepts, role-playing or practice, and feedback...to promote positive interaction with peers” (p. 91). With methodological approaches similar to those of the PMII studies, the research selected to qualify SST as an EBP is frequently structured and manualized (Lopata et. al, 2010). Commonly targeted outcomes chosen as measures of social development focused on recognizing emotions in pictures (Ryan & Charragain, 2010), completing routine-based social exchanges (Laushey et al., 2009), and interacting with multiple communication partners to promote generalization (Belchic & Harris, 1994).

While each of these outcomes are important components of socialization, the autobiographical authors place greater emphasis on other aspects. The authors discuss the importance of beginning friendships based upon mutual hobbies, values, and interests (Elder Robison, 2007; Grandin & Barron, 2005; Shore, 2003; Zaks, 2006). The authors also agree that knowledge about the *types* of friendships helped them to understand their role amid a variety of surroundings and people. Zaks (2006), for example, wrote about the importance of recognizing friends who are close enough to share personal information versus those that should receive more general, casual information. In addition, Zaks and Grandin agree that there is value in learning “rote” social features such as controlling tone of voice, taking turns, and body positioning, but that “memorization of broad social rules doesn’t always help on the spot” (Zaks, 2006, p. 165).

Perhaps the most surprising result of the thematic analysis involves the authors' universal agreement that sensory experiences in the environment can act as a barrier to engaging in social interaction. In each of the autobiographical texts, the authors repeatedly address the challenges associated with meeting new people and initiating and maintaining conversations in environments where external sensory input is overwhelming. Therefore, service providers would need to be cognizant of individuals' sensory preferences as critical features of social intervention planning. Of the NPDC's nine recommended EBPs for social development, only one (i.e., Antecedent-Based Intervention [ABI]) attempts to address attention to sensory preferences as a prerequisite to successful intervention. The NPDC's fact sheet summarizing ABI addresses the importance of conducting a functional behavior assessment (FBA), which may identify environmental conditions that potentially elicit behaviors impeding learning and social interaction.

However, of the 32 single case design studies listed as qualifying evidence for ABI, only four directly employ environmental modifications (i.e., elimination of stimuli that created discomfort, increased access to preferred sensory conditions, use of child choice to determine location for services) as a predictor of participant success (Cale et al., 2009; Conroy, Asmus, Sellers, & Ladwig, 2005; Dyer, Dunlap, & Winterling, 1990; Mason & Newsome, 1990). The remaining 28 studies focused on approaches such as controlling stimuli to decrease stereotypic behaviors (Kennedy, 1994; O'Connor et al., 2011; Walpole, Roscoe, & Dube, 2007), using priming to improve participation (Koegel, Koegel, Frea, & Green-Hopkins, 2003; Schreibman, Whalen, & Stahmer, 2000), and the process of conducting functional analyses (Butler & Luiselli, 2007; Ebanks & Fisher, 2003; Piazza, Hanley, & Fisher, 1996; Stichter, Randolph, Kay, & Gage, 2009; Tiger, Fisher, Toussaint, & Kodak, 2009).

Though the NPDC report lists attention to environmental stimuli as part of ABI, the report's qualifying evidence pays a disproportionate amount of attention to conducting functional analyses of challenging behaviors and therapist-directed techniques (e.g., stimuli control, prompting, priming methods, etc.). Based upon the written experiences of the autobiographical authors, family members and service providers focused on improving social interaction abilities would be better served by attending to potentially confounding sensory factors and developing self-management strategies that individuals may use in a variety of settings.

Finally, the report lists Parent Implemented Intervention (PII) as an EBP; although it is not included as one of the nine that transcends all age groups (the NPDC report endorses PII as an EBP for the 0 to 2 and 6 to 11 age ranges only). Based upon the NPDC's inclusion criteria, PII is not listed as an EBP for each of the age ranges due to the lack of existing research that met the qualifying criteria for inclusion in the systematic review. PII is included in this discussion, however, because each of the autobiographical authors chose to write extensively about the role of their parents and family as important influences on their social development. In ways reminiscent of the earlier discussion about PMII, the authors discuss their ability to choose "who" they learn socialization from as an important factor.

In the 8 group design and 12 single case design studies qualifying PII as an EBP for the 0 to 2 and 6 to 11 age ranges, three studies specifically address the effectiveness of parent training to promote social communication (Aldred, Green, & Adams, 2004; Kaiser, Hancock, & Nietfeld, 2000; Reagon & Higbee, 2009). In contrast, the autobiographical authors each recognize their parents as the people providing the greatest influence when learning about relating to others. Perhaps by offering parent training strategies recommended in the NPDC report (e.g., didactic instruction, modeling, coaching, and performance feedback), service providers take steps toward

providing effective strategies to the people the authors with ASDs identify as the greatest influence.

Recommendations

By applying thematic analysis techniques to autobiographical texts and comparing resultant themes to the recommendations of the NPDC's most recent systematic review, we are able to generate recommendations for intervention and future research:

1. Consider the preferences of the individual with ASD as being equally important to the use of an evidence-based intervention. Provide individuals the opportunity to choose their peers, activities, and environments as the foundation for successful focused intervention approaches.
2. Consider a person's sensory preferences as an essential prerequisite to all learning situations, but especially during activities that include social interaction.
3. Obtain feedback from individuals with ASD about social intervention practices. Perhaps a more comprehensive review of existing qualitative research about social interventions is a first step toward increasing attention to individuals' social experiences.
4. Increase the value of conclusions from traditional quantitative research by incorporating more "real world" evaluation. For example, Pragmatic Clinical Trials (PCTs) allow researchers to measure the effectiveness of a therapy practice during normal, daily routines (MacPherson, 2004).

Conclusion

The development of social interaction skills is a key component of intervention programs for individuals with ASDs. The findings of this study suggest that autobiographical literature

from authors diagnosed with ASDs can be a valuable source of information to supplement published research that employs more traditional qualitative and quantitative methodologies. When considered alongside recommendations from the NPDC's review, the authors' discussions about sensory preferences, peers, family, and social skills training present additional considerations for the development of social interaction skills. Further research is needed to explore ways that the experiences of people diagnosed with an ASD may inform the research and service practices of those who provide intervention.

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Appendix E
Comprehensive Examination III

Using Point-of-View Video to Facilitate Social Interaction between a Parent and Their Child
with an Autism Spectrum Disorder: A Feasibility Study

Keenan Stump, M.S.

Comprehensive Examination III

Abstract

This study evaluated the feasibility of employing video from a child-worn GoPro[®] camera to facilitate communication opportunities between a parent and their child with autism spectrum disorder (ASD). The findings compliment a growing body of research exploring new approaches to the evidence-based intervention for individuals diagnosed with ASD known as video modeling (VM) (American Psychiatric Association, 2013). Consistent with previous feasibility studies, this study employed a single-subject design that allowed for the participant to serve as their own control. The findings indicate that it is possible to design an intervention using video from a wearable camera that is practical to implement while measuring effectiveness. Recommendations based upon these findings are discussed, particularly for future research using a larger sample size as part of a multiple-baseline design.

Keywords: Autism spectrum disorders, Video modeling, Family-based interventions, Social communication, Feasibility study, Single-subject design

Introduction

There is a growing body of research exploring new approaches to the evidence-based intervention for individuals diagnosed with autism spectrum disorder (ASD) known as video modeling (VM) (American Psychiatric Association, 2013). VM is a broad term referring to intervention techniques that provide individuals with opportunities to develop new skills by watching videos, rather than engaging in direct personal experience (Cihak & Schrader, 2008). The body of VM research is consistently subdivided according to three different styles of video production (i.e., video modeling of others [VMO], video self-modeling [VSM], and point-of-view modeling [POVM]). In each of these VM production styles, individuals watch videos that act as a visual (and sometimes audible) support for learning new behaviors.

Researchers hypothesize that one reason for the recent rise in VM popularity is the general public's increasing access to portable technology (Hart & Whalon, 2012; Marcu, Dey, & Kiesler, 2012). The use of portable video creation technologies (e.g., tablets, smartphones, movie editing software, etc.) is becoming an increasingly common practice for service providers and families of children with ASD (Hart & Whalon, 2012; Kagohara et al., 2013; Shane et al., 2012). Additional studies suggest that the societal popularity of portable technologies increases a child's willingness to participate in VM intervention practices while decreasing the social stigma associated with receiving intervention services (Hart & Whalon, 2012; Kagohara et al., 2013; Shane et al., 2012).

Although the majority of existing VM research has focused on the use of videos with peers and adults acting as models, POVM (the production technique that simulates watching an experience from the vantage point of the viewer) is emerging as an effective and accessible

method for teaching new skills to individuals with ASDs (Buggey, Hoomes, Sherberger, & Williams, 2011; Miltenberger & Charlop, 2015).

To date, the majority of POVM studies have targeted the development of personal care/adaptive skills (Shipley-Benamou, Lutzker, & Taubman, 2002), manipulating toys (Hine & Wolery, 2006), and completing functional tasks (i.e., setting the table, transitioning between classes, withdrawing money from an ATM) (Alberto, Cihak, & Gama, 2005; Schreibman, Whalen, & Stahmer, 2000). Application of VM to social outcomes has been less frequent. Although Tetrault and Lerman (2010) employed POVM to teach the social concepts of conversational initiation and turn-taking to individuals with ASDs, the added use of scripts and reinforcement systems led the authors to be unclear about the effectiveness of the POVM strategy.

Despite variations among the methodologies and targeted outcomes of each of the studies listed above, the process of recording videos to simulate the participant's point-of-view involved one of two techniques: (1) the camera is held by a member of the research team from just above or behind the participant during an activity, or (2) the camera is in fixed position to simulate the participant's eye level and records an actor's hands completing a task.

In a pilot study by Marcu et al. (2012), the authors employed a different approach to capturing images from a child's point of view. Rather than using video, the researchers evaluated the feasibility of parents placing wearable cameras on their children with ASDs to capture still images throughout the child's day. The findings indicated that images from the child-worn cameras provided parents with an increased sense of their child's safety, a better awareness of their child's daily activities, and increased opportunities for social engagement with their children (Marcu et al., 2012). Further, the parents consistently reported increases in

communication with their children. For example, by reviewing photographs from the wearable camera with their child, parents reported feeling able to ask more specific questions, resulting in more substantive child responses (Marcu et al., 2012). This finding is consistent with previous research reporting increased volume and accuracy of responses in children with ASD when asked specific questions about previous events, rather than being asked to generally recall as much as possible (McCrory, Henry, & Happé, 2007). Additional research has shown that children with ASDs are less accurate recalling personally experienced events when compared to their recall of witnessed events, suggesting the potential advantages of “re-witnessing” the events recorded by the wearable camera (Millward, Powell, Messer, & Jordan, 2000).

Perhaps in a larger sense, the act of children sitting down with their parents to review and talk about the photographs as a means of increasing social engagement is consistent with previous studies exploring the benefits of using digital photographs to develop storytelling and conversational skills (Landry, 2008; Go, 2007; Vaucelle & Ishii, 2009). These results suggest that incorporating video filmed from the perspective of the child may be a key to improving the child’s ability to share about events and improve the communication experience with their parents.

Purpose

Video modeling interventions targeting communication continue to gain traction as evidence-based practices for individuals with ASD, although empirical investigations that incorporate POVM are limited. Using videos created with a wearable camera is a relatively unexplored area that may prove beneficial and become more accessible to an increased number of families of children with ASD. This study is the first to evaluate the feasibility of employing

video from a GoPro® wearable camera to facilitate communication opportunities between parents and their child with ASD. Specifically, this study asked: Is it feasible to:

1. place a wearable camera on a child and record an outing?
2. video record a parent/child conversation to capture the social interaction?
3. expect that the parent and child will interact about the video of the outing?
4. code the parent/child social interactions captured on video?
5. gather insights from the parent after the dyadic social interactions?

Method

Feasibility

As a prerequisite for a larger study, we conducted a feasibility test. While feasibility testing does not allow for statistically relevant comparisons to existing intervention practices, it has been recommended as a valuable stage in the development of autism-related interventions to assess practical application across sites, acceptability of participants, and measurements of fidelity (Smith et al., 2007).

This feasibility study employed a single-subject design. Single-subject design has emerged as a proven method for establishing an evidence base for autism-related interventions, due in part to the variability that exists among individuals diagnosed with ASD (Horner et al., 2005). By using a method that allows for the participant to serve as their own control, potential relationships between the intervention and associated outcomes become apparent (Portney & Watkins, 2008).

Participants

This study used a convenience sample of a mother and son from a member of the research team's existing caseload with a local therapy service company. Additional criteria used

to select the participants included a familiarity with device technology and a recreational preference for watching videos on a tablet, laptop, or related device.

Alan was a ten year old male in the fourth grade who was diagnosed with ASD in 2007. At the time of the study, he received speech and occupational therapy services at school as part of his Individualized Education Program (IEP) and an additional hour of speech therapy services per week at home.

Alan communicates using both verbal speech and a voice output communication aid (VOCA) (i.e., ProloQuo2Go[®] installed on an iPad[®]). Alan's IEP included goals specifically targeting expressive language and social interaction, using either speech or the VOCA. Alan's parents reported that Alan primarily uses single words to verbally respond to questions or to request preferred items and/or activities. Alan also constructed three- to five-word sentences to request items using the VOCA, although his parents reported that he frequently required verbal prompts to create complete sentences.

Though they expressed concerns about a variety of Alan's physical, social, and academic challenges, a primary goal of Alan's parents was to improve their son's ability to tell them about daily events.

Settings

This study involved two settings. First, we collected the real time video with Alan recording POV video for ten to fifteen minutes of a preferred activity (i.e., walking around a nearby train station with an attached shopping center). Secondly, we met in the family's kitchen to complete the baseline and intervention procedures.

Procedures

Alan's family met with the first author and received an approved Institutional Review Board consent document. The participants then worked with the first author to schedule time for Alan to record the POV video, as well as the baseline and intervention visit. The first author collected data by video recording and transcribing the parent/child interactions in baseline and intervention phases of the study.

Findings

The overall goal of this study was to evaluate the feasibility of employing a GoPro wearable camera as a means of recording a child with ASD's outing so that the parent and child can view and discuss the outing using the video. In addition to documenting procedural considerations that answer each of the original five feasibility questions, we were able to derive some preliminary insights about the effectiveness of the intervention from transcriptions of the sessions and the parent interview.

Regarding Feasibility

Is it feasible to place a wearable camera on a child and record an outing? A member of the research team used a cell phone equipped with the GoPro® App to observe the camera's view and remotely control the recording function. We initially attempted to affix the GoPro® camera to the portion of the backpack strap that goes over and in front of Alan's left shoulder using a GoPro QuickClip®. Given the weight of the camera and the pliable material of the strap, the camera tended to tip forward. This resulted in video images that more closely resembled the viewpoint of a person looking downward, rather than forward. Instead, we mounted the camera on a GoPro® chest harness, which provided a better representation of Alan's visual perspective. Alan did not object to wearing the chest harness.

Is it feasible to video record a parent/child conversation to capture the social interaction? We considered the procedural elements of this question as they applied to the baseline and intervention conditions.

Baseline video. In order to record the parent child interaction in the baseline condition (without the POV video), the first author placed a single GoPro® video camera on a shelf approximately six feet away and facing the places where Alan and his mother usually sit at their kitchen table. Alan was not in the room at this time, but his mother sat in her chair to ensure that the camera was adequately positioned to capture both individuals. This angle provided a more conventional viewpoint of the participants' faces during their interaction. After placing the camera and pressing record, the first author left the room for the duration of the parent/child interaction in an effort to maintain the authenticity of the natural setting. At one point, however, the camera's blinking red light distracted Alan, who attempted to stand up and walk to the camera. His mother asked that he remain in his seat and leave the camera alone, and Alan did not attempt to approach the camera again.

Intervention video. During the intervention condition, we positioned an additional GoPro® camera to record the interaction from behind the pair and with a view of the iPad® screen. The second camera provided researchers with information about what Alan and his mother looked at while talking with each other (e.g., POV video). In order to avoid the distraction of the blinking red light while recording as was observed during the baseline condition, we covered both cameras' red lights with a small piece of black tape. Again, the first author left the room for the duration of the parent/child interaction in an effort to maintain the authenticity of the natural setting. Therefore, we decided it is feasible to video record

parent/child conversation and capture the social interactions with adjustments (i.e., covering the light and remaining in the chair).

Is it feasible to expect that the parent and child will interact about the video of the outing? After video recording the interaction between Alan and his mother in the baseline condition (without the POV video), the lead author briefly coached Alan's mother about viewing the POV video on the iPad's® playback software. Similar to the baseline condition's instructions, Alan's mother was told to interact naturally with her son (although they would be watching Alan's POV video together this time). A comparison of the number of interactions in baseline and intervention conditions revealed that Alan and his mother interacted for a longer period of time during the intervention condition, suggesting that it is feasible to expect that the parent and child will interact about the POV video of an outing.

Is it feasible to code the parent/child social interactions captured on video? We developed a turn-based coding system (i.e., conversational dyads) to operationalize the interaction between Alan and his mother.

Conversational dyads. For the purpose of this feasibility study, researchers coded the child's responses to the parent's question/comment. We called this transaction a *conversational dyad*. As in all conversations, sometimes the parent or child would make more than one comment/question within each persons' turn to talk. Here is an example of one conversational dyad:

Parent: *Who did we see? Did we see daddy?*[two questions = one turn]

Child: *Daddy? No.*[one question, one comment = one turn]

Coding instrument. In order to determine whether it was feasible to code video interactions reliably, the researchers created and validated a coding system. The researchers

utilized a cohort of five interdisciplinary doctoral students to create dyadic conversation codes. After practicing the coding process using transcribed data from each condition, the cohort's feedback resulted in three codes developed specifically for this study. The child's responses in each dyad were coded to be a *conversational match (M)*, a *conversational match with prompts (MP)*, or a response that *does not match (DNM)*. Appendix A summarizes the criteria used to categorize each of the conversational dyad responses.

With the coding instrument designed, we then asked a speech therapist with a background in ASD and communication disorders to be a second rater, coding 100% of the data in the baseline and intervention conditions using the code developed and validated with the doctoral student group. The rater was blinded to the code development process. We calculated reliability between raters by measuring agreement on classification of the child's responses, expecting a kappa coefficient of .90 in each condition. Kappa coefficients of .97 in the baseline condition and .95 in the intervention condition exceed our expectations. Therefore it is feasible to systematically code interactions captured on the video.

Is it feasible to gather insights from the parent after the dyadic social interactions?

After completing the recorded interactions with Alan, his mother participated in a qualitative interview about her experience for approximately 25 minutes. Based upon Alan's mother's answers to the interview questions, she believes a wearable camera may provide a better understanding of how Alan experiences the world and offers her an increased sense of her child's safety. In addition, Alan's mother stated that she was happy to participate in the study and to be given an opportunity to share her thoughts about the study's procedures and potential future applications of wearable camera technology. It is feasible to gain additional insights from the parent after the dyadic social interactions; we discuss these insights below.

Additional Insights About the Effectiveness of the Intervention

We transcribed both conversations, providing a way to look at data comparing features of the parent/child conversation without the visual support of POV video (baseline condition) to their conversations with POV video (intervention condition). After establishing interobserver agreement, we calculated the frequency of each code (i.e., M, MP, and DNM). The omnibus chi square analysis revealed a significant difference $\chi^2(2, N = 115) = -0.49, p < .001$ in the distribution of conversational dyad codes comparing the baseline (expected values) and intervention (observed values) conditions. We conducted pairwise comparisons to reveal differences between the frequencies of each of the three conversational dyad codes in both conditions. To neutralize the challenge of making multiple post hoc pairwise comparisons, we selected a post hoc Bonferroni correction (.05/3 tests = .016).

Alan had significantly more responses that *did not match* (DNM) during the intervention condition ($p = .003$); there were no significant differences when comparing frequencies of the remaining two conversational dyad codes (M and MP) in each condition. Comparisons of the raw frequencies of codes in each condition and the results of the pairwise comparisons are depicted in Figure 1. Additional comparisons of the conversations during each condition revealed further differences (e.g., increased duration of shared activities [i.e., joint attention], decreased number of yes/no questions, etc.). Table 1 portrays these conversational characteristics and Figure 2 illustrates a comparison of the characteristics' per minute frequencies. These data and the parent's comments led to some preliminary insights.

Table 1

Results

<u>Characteristic of Conversation</u>	<u>Baseline Condition (Without POV Video)</u>	<u>Intervention Condition (With POV Video)</u>
Elapsed Time of Interaction	6:03	12:51
Number of M (%)	19 (36%)	18 (29%)
Number of MP (%)	28 (53%)	21 (34%)
Number of DNM (%) *	6 (11%)	23 (37%)
Parent Questions per Minute	11.7	7.4
Dyads per Minute	8.7	4.8
Parent Yes/no Questions	32 (5.3 per minute)	44 (3.4 per minute)
Child Yes/no Responses	14 (2.3 per minute)	11 (<1 per minute)

* (p. = .003, significant difference based on Bonferroni correction to .016)

The parent and child spend more time interacting when they have a POV video. With the support of the POV video (intervention condition), the overall length of time of the parent/child interaction more than doubled to 12 minutes and 51 seconds, compared to their interaction lasting 6 minutes and 3 seconds without the POV video (baseline condition). This increase in the duration of time that Alan and his mother interacted suggests that their joint attention to the POV video provided increased conversational opportunities. This finding is consistent with recommendations of previous research stating that joint attention is a necessary component of sustained conversation (Charman, 2003; Pickard & Ingersoll, 2015; Sodian & Kristen-Antonow, 2015).

The parent asks more specific questions when there is a POV video available. Likely because of the support of the POV video, Alan's mother prompted responses from Alan less. Perhaps the video was more visually supportive and the video allowed Alan to respond to more specific questions that did not require additional prompts from the parent. Consistent with the approaches of previous research, we coded yes/no questions as prompts to elicit Alan's responses

(Funazaki & Oi, 2013; Neef, Walters, & Egel, 1984; Oi, 2008). Despite the fact that the time length of their interaction more than doubled when they shared the POV video, there were corresponding decreases in the frequencies of the parent's yes/no questions and Alan's yes/no responses. This shift in the type of questions/responses further suggests that viewing the POV video allowed Alan's mother to ask about more specific detail from her son's experience, leading to more complex responses.

The parent asks less questions when there is a POV video available. In addition to changes in the types of questions during the intervention condition, there were decreases in the number of dyads per minute (8.76 during baseline to 4.82 during intervention) and parent questions per minute (11.57 during baseline to 7.54 during intervention). By decreasing the number of her questions, Alan's mother allowed more time for Alan to receptively process the questions and formulate responses. Additionally, perhaps the visual information from Alan's POV video decreased his mother's repeated attempts to find a novel topic that might spark Alan's interest and encourage his responses.

Alan's mother reported that a frequent cause for concern in their family relates to Alan's experiences away from home. She stated that the school will occasionally send notes home that report about incidents when Alan will protest participating in certain activities or refuse to answer adults' questions. Based upon her own experiences, she knows that Alan will sometimes refuse to do something because he was asked to follow too many directions, which makes him unclear about others' expectations. She believes that seeing Alan's POV video would provide her the opportunity to offer guidance for caregivers about Alan's language processing and improve consistency with communication:

“I can’t, obviously, internalize the way he internalizes, but you can kind of see how things are presented to him. Are things presented in a friendly manner, is someone talking too fast or making things super confusing...you know?”

The data suggest that ‘echolalic’ responses may have meaning for the child. An interesting result of this study is the significant increase in the number of Alan’s responses coded as *Do Not Match* (DNM) when interacting with his mother during the time that they viewed his video together (6 in baseline vs. 23 in intervention, an increase of 283%). A closer examination of the transcript of the intervention condition reveals that 7 of the 23 dyads coded as DNM in the intervention condition take place during one section of the video. In each of the seven consecutive dyads coded DNM, Alan says “zig” or “zigzag” in response to his mother’s questions/comments.

Alan’s verbal repetition of certain words and phrases is a common trait among individuals with ASDs (sometimes referred to in the literature as perseverative speech or echolalia) (American Psychiatric Association, 2013; Stiegler, 2015). Although there is no consensus explanation for the prevalence of repetitive speech among those with ASDs, recent findings continue to elucidate the communicative functions of repetitive speech. Literature suggests that the repetition of words, phrases, and music, etc. serves a communicative purpose (Sterponi & Shankey, 2014; Stiegler, 2015). Indeed, Alan’s mother reports that Alan will frequently repeat dialogue or songs from his favorite videos as a means of requesting or refusing.

The data suggest potential explanations for his repetition, and the increase in DNM responses in the intervention condition. One hypothesis for Alan saying ‘zigzag’ is that he was attempting to initiate new conversation about the video. The portion of the video that Alan and his mother are watching during his string of repeated phrases contains a hallway where the floor

consists of bricks arranged in prominent zigzag pattern. While impossible to confirm, we can propose that Alan's repetition of that unique phrase during this one specific stretch of video is due to that pattern's prominence in the video at that time.

If saying 'zigzag' is a true attempt to direct his mother's attention to the pattern on the hallway floor, the POV video served as visual support for Alan's independent initiation of a new topic. Our coding process did not account for this possibility and so each occurrence was accurately coded as DNM. If it was a true attempt at initiating conversation, then Alan's visually supported communicative intent is consistent with numerous studies describing the benefits of visual supports to increase expressive communication from individuals with ASDs (Ganz et al., 2012; Ganz, Kaylor, Bourgeois, & Hadden, 2008; Reichow & Sabornie, 2009).

Alan's mother validated this hypothesis with her insights. She spoke of her surprise about the portions of the video that seemed to hold the most interest for Alan. She was curious to know why he was so interested in parts of the video that depicted his walking transitions between activities (e.g., the zigzag flooring in the hallway); she assumed Alan would have been interested in the activity portions of the video:

"It was weird that he was so interested in the getting to the places instead of the places where you were already experiencing something. I would be curious if we went on a 2 mile walk or something, like on a path or on a trail, to see what he would be interested in going back to check out on the video."

She discussed the challenge of being parents that are always making guesses about what their child actually enjoys when they spend time together. As an example, she explained that their family attended an air show the previous day. She described that she and her husband were surprised that Alan was more entertained with tossing small rocks over a nearby fence than the

jets speeding by overhead. She felt that the air show experience, in combination with his preferences for watching the walking transition parts of the video, provided new ideas about what her son might find enjoyable:

“Maybe that’s something we’re missing. Like maybe we should be working on bike riding or, you know, an activity that he finds interesting and that satisfies his needs for *his* type of adventure.”

The child may have the opportunity to direct the conversation when the POV video is available. The other hypothesis for the increase in DNM responses also relates to the visually supportive nature of the POV video. Ten of the remaining 16 dyads were coded as DNM because Alan was moving the playback bar to different parts of the video, rather than verbally responding to his mother’s questions. Once again, these instances may be Alan’s non-verbal attempts to initiate new topics by drawing his mother’s attention to certain parts of the video. Our coding system, however, required that the absence of a verbal response be coded as DNM. In the future, the coding process needs to account for the possible use of visual supports as appropriate conversational turns.

While discussing her experiences viewing the video with her son, Alan’s mother also shared ideas about ways that POV video could be used for expressive communication. Alan’s mother reported that she frequently witnesses her son’s frustration with communicating his preferences to others. In many instances, she believes that he wants to ask for specific items or activities that are difficult to request verbally and that may not have an associated picture within his VOCA. She considered the possibility that a catalogue of POV videos may provide an additional way for Alan to communicate:

“I would be curious to see if he would go back and watch that. So if I asked him, ‘What do you want to do today?’ he could go back and be like, ‘I want to go on this trip or I want to go on this trip,’ because he would have choices.”

Discussion

This study confirmed the feasibility of employing video from a GoPro® wearable camera to facilitate communication opportunities between a parent and child with ASD. The findings also indicate that it is possible to design an intervention that is practical to implement while measuring effectiveness. Additionally, we created a dyad-coding structure with strong reliability that could be adapted for future studies.

In terms of the intervention’s effectiveness, the findings suggest that a parent and child with ASD experience a different conversation about the child’s experiences when sharing the POV video. We sought to answer questions about feasibility, we cannot make generalized conclusions about the effectiveness of the intervention. However, the increased amount of time that Alan and his mother remained engaged with the video modeling activity contributes to emerging evidence that supports the use of personal video production technology as intervention tools in the home environment (Cardon, 2012). Furthermore, Alan’s attempts to direct content on the screen during playback may indicate a willingness to initiate new topics of interest, rather than simply responding to parent questions. Such a finding would support research suggesting that individuals with ASD visually attend to different items in a visual field when compared to people not on the spectrum (Cardon & Azuma, 2012; McPartland, Webb, Keehn, & Dawson 2011; Tsatsanis, 2005). Future research exploring such possibilities would be beneficial to families, therapists, and other caregivers.

Recommendations for Future Research

1. Provide options for participants based on their preferences for attaching the camera to the child.
2. Utilize black tape or a night time camera case when recording the parent and child interaction to avoid the potential distraction of the blinking red light.
3. Consider other authentic life activities that could capture children's experiences that might be a source of conversation later (e.g., playing with siblings, playing with the dog, riding in the car).
4. Revise coding key to include child-initiated topics as an appropriate conversational response, rather than measuring verbal responses as the only product of the parents' questions.
5. Revise coding key to allow the child the opportunity to position the video so that the child may direct conversation via the content on the screen.
6. Employ a larger sample size as part of a multiple-baseline design to observe the potential effects of the intervention across settings and participants.

Conclusion

Conducting feasibility studies is a key component to the creation of intervention programs for individuals with ASDs. These findings contribute to a growing body of literature supporting the use of portable video modeling technologies as effective tools to encourage social interaction among individuals with ASDs and their families. Further research will need to more directly address the limitations of this study, including small sample size, convenience sampling, and the importance of observing the effects of the intervention over time.

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