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Communicating in “Co-operation” with a Nonverbal Bilingual Teen with Autism

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My research on autism stems from the need to address the lack of acceptance of social, linguistic, and communicative diversity. For the past two years, I have been volunteering with Oxnard Special Populations, an enrichment program in my hometown for mostly low-income Latinx children and youth with autism and other developmental conditions; the program promotes social skills through recreational activities. As a volunteer, I engaged with many individuals with autism who demonstrated high levels of communicative and social competence. I became fascinated by how “José”, a particular nonverbal (i.e. non-speaking) Latino teen with autism in the group used various communication resources such as a computer tablet, home sign language, and receptive bilingualism to communicate with his peers, an aide, and his bilingual family. José demonstrated to me that his way of interacting and communicating is just as valid and important as speech. In response to the lack of diversity in autism studies, I have dedicated my undergraduate career to researching José’s competencies in order to shed light on his complex methods of effective communication and social interactions.

For this research project, I utilized a wide range of methods and strategies to find relevant resources. Due to the nature of my research, I made use of a variety of different disciplinary databases. First, I first began searching for relevant peer-reviewed research articles through the PsycINFO database. Here, I found an abundance of research articles about autism. However, most of these articles were taking an experimental, clinical, intervention-driven, and deficit-based approach to studying autism. This exposure to autism studies in Psychology was extremely helpful for my research because I used these articles to discuss the overwhelming amount of autism literature that focuses on the deficit perspective. Because my research is more interested in revealing the strengths and capabilities in autism, I searched for resources in other disciplines, such as Linguistics, Communication, and Anthropology. For example, through the library website, I

used databases such as Linguistics and Language Behavior Abstracts, Communication Abstracts, and AnthroSource. In my search, I found a few articles that did examine the competencies of autism through a linguistic-anthropological perspective, such as work by Olga Solomon, Elinor Ochs, and Laura Sterponi, who are all major contributors to this area of research. After reading their articles, I also made use of their reference page, finding even more articles related to the subject. However, I noticed that there was a consistent gap in the literature. Throughout my search for relevant published research articles, I found that there were several studies focusing on bilingual children with autism, but they were mainly interested in “high-functioning” verbal children. There were also several studies that I found that were focused on nonverbal communication and autism, but few examined nonverbal children with autism. And no research focused on nonverbal bilingual teens with autism.

With time, I became much more comfortable using the databases and learning ways in which I could efficiently search for relevant articles that were manageable in amount. Whenever a research article was unavailable through the UC-elinks, I would use Interlibrary Loan to receive an online version of the article I was interested in reading. In addition to searching for articles through the databases, my faculty advisor, Dr. Mary Bucholtz, would frequently send me relevant articles to read, which enhanced my understanding on the area of research. Through the McNair Scholars Summer Program, I also had the opportunity to gain more practice with using the databases and finding both published articles and books as well as doctoral dissertations. And as an interdisciplinary researcher, it was crucial for me to learn and master several kinds of databases to ensure that my research project reflected all perspective that have contributed to this line of study. Once I found the articles that I was interested in, I used a reference manager, Mendeley, to not only keep my citations organized but to also annotate all of my notes during my readings and

highlight important findings. Ultimately, the library website was at the center to finding my references for this project, thus allowing me to become more efficient in finding relevant articles that have enriched my research.

Communicating in “Co-operation” with a Nonverbal Bilingual Teen with Autism

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Abstract

In his innovative work on the communicative competence of nonspeaking individuals, Goodwin (2004) argues that these often-marginalized people have a wider communicative repertoire than their limited speech would indicate. This reality challenges existing views of the interactional limitations that nonverbal individuals possess. Without speech, they are able to effectively utilize alternative methods of communication to convey meaningful messages, thus allowing for active participation in interaction. Adding to their marginality, some individuals who are classified as nonverbal are also on the autism spectrum; therefore, they are widely viewed as linguistically, socially, and communicatively incompetent (e.g., Baron-Cohen et al., 1985). Yet no existing research examines the way that interactions unfold between nonverbal bilinguals with autism and their family members, contexts that can reveal their competence. Using detailed interactional analysis, this project examines how a nonverbal, Spanish-English-bilingual Latino teenager with autism, who is highly marginalized for both his social abilities and his communicative repertoire (cf. Capps et al., 1998), co-constructs meaning by “co-operating” with family members in his quotidian interactions (Goodwin, 1995; Goodwin, 2017). The analysis focuses on instances where the focal participant attempts to communicate something to his family (e.g., a desire, thought, or emotion), and family members must collaboratively build from his contribution in co-operation in order to reach a successful conclusion. Thus, the focal participant consistently shapes his social world in ways that enable him to be understood by others (Belek, 2018). The findings therefore challenge social deficit ideologies of nonverbal and autistic individuals.

Introduction

Autism is broadly characterized as a neurodevelopmental condition in which persistent deficits in social communication and restricted, repetitive behaviors occur (American Psychiatric Association, 2013). Although most of the current autism literature is clinical and deficit based (e.g., Baron-Cohen et al., 1985), recent research has shed light on the rich social lives of individuals with autism (e.g., Bagatell, 2010; Solomon, 2010; Belek, 2018). Ochs and Solomon (2010) propose the term “autistic sociality,” which they argue is not an oxymoron. Autistic sociality refers to the notion that every child is born with the potential for sociality, but some, such as people with autism, are best able to participate socially under certain conditions. Based on the results of an interactional study of children severely impacted by autism, these children are, indeed, capable of sociality, as they possess a great range of possibilities for “social coordination” that is not only shaped by autism, but also “by the sociocultural practices of the communities they inhabit and the interlocutors with whom they interact” (Ochs & Solomon, 2010). The authors suggest that those severely impacted with autism, especially those who do not produce speech to communicate, display their sociality when they communicate in their preferred modalities in order to reach their social potential.

Several clinical studies of autism recognize that embodied communication is crucial (e.g. Capps, 1998). Interactional analysis is therefore necessary to investigate the communicative capacity of these individuals and their interlocutors. In addition to challenging the way we view autism’s core features, this methodology enables us to consider the ways social and communicative “deficits” are, in fact, effective and powerful in and of themselves (Sterponi & Shankey, 2014).

This research informs Goodwin’s (2017) concept of “co-operative action,” which he

describes as the process in which we borrow our conversation partner’s words and actions and build on one another, creating something new and innovative. Co-operative action is not restricted to language. Rather, it is an essential aspect of all social life of individuals.

Building on a previous pilot study that examined the basic communicative tools and interactional competence of a nonverbal bilingual teenager with autism (Prado & Bucholtz, 2018), this ethnographic case study examines how family members communicate in co-operation with a nonverbal bilingual teenager with autism, José. In the analysis below, the family participants repeatedly try to determine what José wants or needs using sequential guesses. José uses multiple nonverbal communicative strategies both to signal his desires and to indicate when a guess is right or wrong. The analysis demonstrates that nonverbal communicative strategies that are often overlooked by researchers are just as important and even as powerful as speech in everyday social life.

Methodology

José is male and was 14 years old at the time of data collection. At the age of three, he was diagnosed with autism. José is classified as “nonverbal,” meaning that he does not produce speech to communicate with others. Instead, he uses various alternative methods of communication such as a computer tablet app (Proloquo2Go), home sign language, and receptive bilingualism. José lives with his parents and his older sister in Southern California. He is being raised in a bilingual home where both Spanish and English are spoken. His mother is fluent in Spanish and prefers to speak in that language. She understands English and occasionally uses words, phrases, and the communication tablet app buttons to communicate with José. However, she generally speaks with José in Spanish. Moreover, José’s older sister is fluent in both Spanish and English and tends to speak to José in both languages, and sometimes in Spanglish. When

their mother is present, José’s sister tends to use more Spanish. José’s father, although present in the household, opted out of video recordings.

I knew the participating family prior to the study. José and his family are frequent participants in an enrichment program in Southern California where I volunteer; the program offers recreational activities to help with the development of social skills of youth with autism and children with other conditions. In fact, José’s older sister, a good friend of mine, informed me about this volunteering opportunity after she learned about my interest in helping youth with special needs.

Through this program, I was introduced to the highly complex ways that José was able to communicate efficiently with coaches, volunteers, teammates, and family members, all without the use of spoken language. I collected video recordings of family interactions with José in the home because this method gives José and his family the space to demonstrate how they, on a day-to-day basis, significantly challenge the accepted wisdom about core features of autism.

As a case study, the research does not imply that the way in which José and his family communicate is the same for every family with a nonverbal bilingual child with autism. Rather, it demonstrates in detail how each individual is competent in their interactions in their own individualized ways.

In order to collect data, I asked José’s mother and sister to video-record their day-to-day interactions with José. I provided them with a few ideas of what the recordings might possibly consist of. For example, I suggested that they could place the camera near the kitchen table to record lunchtime interactions (Solomon, 2010). I also recommended video-recording daily routines such as getting dressed, getting ready for school, doing chores, and helping out in the kitchen.

The video data I received consisted of a variety of activities: lunchtime interactions at the family’s dining table, daily routines, chores, interactions with the family dog, and walks at the park. The videos were recorded for three consecutive weeks. In most videos, José’s computer tablet is in use, sometimes by only José and other times by “Sister” or “Mom”. I received several videos of varying lengths—from 30-second clips to 17-minute-long continuous videos. I collected approximately four-and-a-half hours of video data. I indexed and coded the entire data set with attention to the interactional details. Unfortunately, information about the date and time of recordings was not systematically noted, so the relative order of some videos is unclear. My absence at the time of recording may have enabled more natural interaction between family members and also allowed them to select what they were comfortable showing. Consequently, the family may have decided to film and share specific interactions and not others with me, the researcher, in mind. In addition, the presence of the camera itself, especially when it was hand-held by a participant, inevitably affected the interaction.

Analysis

Building on Goodwin’s (1995, 2004) work, the following interactional analysis examines instances in which José is attempting to communicate his needs and wants, which leads family members to go through a sequence of steps with the goal of reaching a successful conclusion. The analysis demonstrates that José’s family members have developed a highly personalized and complex method of communication that enables them to effectively communicate with José despite his limited ability to produce spoken language. The transcription conventions in this article were informed by the Jeffersonian transcription system as well as the Santa Barbara system for discourse transcription (Du Bois 2011).

.	falling intonation
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,	level intonation
?	raising intonation
:	lengthened segment
^	raised pitch
@	laughter pulse

Co-operating in family interaction

The following example illustrates how family members co-operate with José. In the excerpt, José is seen trying to communicate something to his sister. As Mom holds the video camera, Sister goes through a sequential series of co-operative actions with José to attempt to reach a successful conclusion. The video-recording opens with José holding his computer tablet and Sister asking him what he wants.

1.	José:	<looks at Sister>	
2.	Sister:	((off camera))	¿Qué ^quieres? 'What do you want?'
3.	José:	<looks at Mom, then at communication tablet. Taps on computer tablet>	
4.	José via tablet:		Yes.
5.	Sister:	<walks closer to José, now in frame>	
6.		<José continues to look at computer tablet>	
7.		<taps on tablet, points to an option on tablet>	¿Quieres comer? 'Do you want to eat?'
8.		<looks at José, back to tablet>	
9.	José via		Help.

	tablet:		
10.		<looks at Sister, making mutual eye contact>	
11.	Sister:	<scrunches eyebrows together ((confused look))>	Help?
12.	José:	<looks at camera, while tapping the back of the tablet. Looks at dog>	
13.	Sister:	<lifts hand, palm facing up. Continues to look at José>	What do you need ^help with?
14.	José:	<looks at camera, then to tablet>	
15.	José via tablet:		<i>Help.</i>
16.		<looks at Sister. Holds her hand, bringing it close, smiling>	
17.	Sister:	<lifts eyebrows, eyes widen, smiles>	@@
18.			What do you ^mea:::n?
19.		<José and Sister look at the tablet>	
20.		<both let go of hands>	
21.		<Sister taps on the tablet>	Aver 'Let me see'
22.	José:	<presses lips together, looks at the camera, then at tablet>	
23.	Sister:	<makes a face of disgust after dog licks her face>	
24.		<Sister stops tapping on tablet, looks up at José, then back at tablet>	
25.		<José continues to look at tablet> <lifts hand, palm facing up. Brings hand down. Looks at José, then back to tablet>	¿Qué quieres? 'What do you want?'

26.	José:	<looks at tablet, fingers hovering over for two seconds>	
27.		<looks at camera, then back to tablet>	
28.	Sister:	<looks at José. Lifts hand, palm facing up>	
29.			I. Want.
30.	José:	<fingers hover over the tablet>	
31.		<looks up at Sister, smiling with an inhale>	
32.	Sister:	<exaggerated smile>	
33.	José:	<looks down at tablet>	@@@
34.	Sister:	<looks at camera (Mom?), smiling>	
35.	José:	<looks at Mom, smiling>	
36.	Mom:		Dilo, (José) 'Say it, José.'
37.		<Sister and José look to tablet>	
38.	José:	<fingers hover over the tablet>	
39.	Mom:		¿Qué quieres? 'What do you want?'
40.	José via tablet:		<i>Hug.</i>
41.	Sister:		Un hug? Okay, big hu::g 'A hug?'
42.		<Sister and José side hug>	
43.			Okay, ya? 'Okay, there?'
44.		<José walks away>	All done?
45.		<José sits at his computer>	

The excerpt demonstrates how Sister and José are able to successfully co-operate and co-construct in a highly complex conversation. The interaction begins with Sister asking José what he wants (line 2). When Sister asks this question, José instantly turns to the video camera, which is held by Mom (line 3). When Mom does not say anything in response to the eye gaze, José’s attention turns to the computer tablet. Via the communication tablet, José responds with, “Yes” (line 4). Prompted by this response, Sister comes into frame, walking closer to José and begins pressing on the tablet that José is holding. Although the angle of the video does not allow for a clear view of what Sister is doing on the communication tablet, it can be implied that Sister is moving the communication tablet screen to a different page in order to try to direct José to say what Sister thinks he wants to say. When Sister asks José if he wants to eat (line 7), she points to the tablet, indicating that she changed the page to display the potential options she thinks he may use. Using Sister’s previous action, José responds with “Help” (line 9). Sister gives José a confused look, demonstrating that this response was not what she had expected since she asked a closed question but received neither a yes or no.

Instead, Sister must now use this information given to her by José to decide what the next move in the interaction will be. Sister decides to reuse what José had said but adds in a question mark at the end (line 11), thus reusing what was previously stated and transforming it into something new. She adds the lifting of her hand for emphasis on the question (line 13). When she does not get a clear response from José that she understands, she resorts to asking the question differently: “What do you need help with?” (line 13). Here she reuses what she had previously said and transforms the “help” into something new. With this, José again instantly looks to the camera in Mom’s direction, almost as if the answer lies within her. Looking in Mom’s direction when asked this question, as well as in line 14, may be interpreted as an attempt

to demonstrate that he acknowledges the camera and needs help understanding why it is pointed towards him. Therefore, this response may not be as unconventional as first assumed. Regardless of this interpretation, José, via communication tablet, asks for help again and immediately takes Sister’s hand, smiling (line 16). This catches Sister by surprise and she laughs, asking what he means by this action (lines 17-18). As José holds her hand, he also slightly pulls her hand towards the tablet, thereby overcoming the linguistic limitations of the tablet by embedding this gesture into the interaction. After realizing that this tactic does not work efficiently, Sister says, “Aver” (“Let me see”) in order to continue co-operating in this interaction. Sister begins moving the tablet pages again to try to find a page that has what she believes he wants, with the intention to make it easier for José to tell her. This demonstrates how Sister helps facilitate the interaction in order for it to reach a successful conclusion.

Sister’s method of co-operative action illustrates that she also looks for assistance from Mom. Sister again asks José what he wants, but José hesitates. He continues to look in Mom’s direction, but again receives no response from her, and therefore he resorts to looking at the tablet. After receiving no response from José, Sister uses the same hand gesture to emphasize that she is waiting for a response. When still no response is given, she gives the beginning phrase, “I want,” with a prominent emphasis on each word in an attempt to help facilitate the conversation. When José looks up from the tablet and gives Sister a smile (line 31), he may be demonstrating that the communication tablet, though a useful tool, is also limiting in its button options. It may not reflect what he wants to express, and therefore he needs to hesitate to get the point across. At this point in the interaction, Mom intervenes, building from this silence by saying, “Dilo, José” (“Say it, José”; line 36). From this, José builds his own action of hovering his fingers across the tablet. In order to encourage José to use the tablet, Mom asks him what he

wants, to which José responds, “Hug” (line 40). Sister then co-operates by recycling what José has said to ask her question: “Un hug? Okay, big hug.” They then hug each other (line 42), demonstrating how they have built the conversation together to reach this point. When Sister asks, “Okay, ya?” (“Okay, there?”), José co-operates with Sister by answering with his body. He physically leaves the conversation to sit at his computer, thus demonstrating to Sister that the conversation is now over. This interaction shows José and Sister’s ability to co-operate in their daily conversations in ways not thought of before, and shows their interactional competence that defies common beliefs about individuals with autism.

Discussion

Although José does not produce spoken language, the analysis demonstrates how he consistently challenges linguistic, social, and communicative deficit ideologies of autism by revealing his interactional competence in everyday life through co-operative action. As an effective nonverbal speaker, José participates and engages in meaningful social interaction with his family. During instances of miscommunication in his interactions, José guides his Sister and Mom through a series of sequential guessing, thus overcoming linguistic limitations in order to reach a successful conclusion. The communication tablet that José uses, although useful, is also limiting and can miss the richness of his linguistic repertoire. He is also able to use the previous actions of actors and build upon them, a process that requires social and communicative competence to achieve, and an ability that is nonexistent in most autism research findings.

Similar to Goodwin’s (2004) “competent aphasic speaker who can’t speak,” José’s competence does not lie within himself alone, but is deeply embedded within the actions of others; both Mom and Sister help facilitate the interaction through co-operative action in order to

reach a mutual understanding of José’s needs. Sister uses José’s previous actions and reuses, supplements, and transforms them to keep the conversation going with the goal of understanding what José wants. In several instances, Sister uses José’s nonverbal and verbal co-operative contributions to decide how to approach the interaction. She guides José into what she believes he wants, yet José demonstrates that he is in fact an active participant by guiding Sister as well when her sequence of guesses is far from what he wants.

In this interaction, José uses multiple forms of communication such as the communication tablet, eye gaze, facial expressions, hand gestures, and more. Family members are able to use their own communicative resources, specifically the framework of co-operative action, to collaborate with José in the process of unraveling instances of miscommunication. This co-operation is effective as they co-construct conversations in order to overcome linguistic limitations. Together, they are able to achieve a highly complex interaction that requires the collaboration of both parties; however, this does not minimize José’s ability to be an active, competent speaker. He demonstrates this through his ability to construct the conversation on his terms, as well as through his personalized communicative capabilities.

Conclusion

This study investigates how family members in a Latinx home co-operate with a nonverbal bilingual teen with autism. By video-recording José’s interactions with his family members at home for multiple weeks, I created the first study that I am aware of that examines the interactional competence of these highly underrepresented and underserved individuals. José reveals how he consistently shapes his social world in a way that caters to his needs. This allows for family members to dive into José’s world rather than aim for “neurotypical” ways of communicating and sociality. José’s ability to efficiently interact with family members allows

him to challenge social deficit ideologies of autism. By doing so, José empowers this specific population, showing them in a more positive light, with wider linguistic, social, and communicative repertoire than originally indicated in previous autism studies. Family members play a vital role for José to achieve interactional competence by helping facilitate the interaction when instances of miscommunication occur.

Because José demonstrates his ability to engage in meaningful conversations with family members, this study has further implications for personalized communicative interventions. Clinical interventions aim to equip individuals with autism with a communicative tool belt that only has socially “acceptable” and “appropriate” ways of communicating. This approach of “fixing” autism by restricting individuals to only certain ways of sociality minimizes other forms of sociality, such as José’s diverse form of sociality; however, José demonstrates that the way he communicates is just as effective and valid. The privileging of speech misses the importance of embodied and collaborative social communication in the social interaction of nonverbal autistic individuals.

Future research must delve deeper into the strengths and capabilities of nonverbal individuals with autism, specifically in Latinx communities, in order to have a better understanding of their social and communicative competence and how culture plays a role in their daily lives. Studying the interactions of individuals like José is an important step to reaching a greater understanding of the interactional competence of these individuals, and how social actors help them reach their social potentials.

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