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What's wrong with Me?: An Autoethnographic Investigation of the Co-Cultural Communicative Practices of Living with Tourette Syndrome during Adolescence

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Abstract
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Keywords
Autoethnography, CoCultural Theory, Tourette Syndrome, Bullying, Identity, Disability, Education, Discrimination, Adolescence

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Using an Autoethnographic methodology, this essay explores how I was diagnosed with Tourette Syndrome. My experience illustrates a dynamic and difficult process of understanding and negotiating assimilation, using a variety of communication strategies related to self-perception, perceptions of others, and interactions with others. Using Co-Cultural theory (CCT) as a theoretical framework, three themes emerged from my experience: (1) nonassertive assimilation: negotiating with relationships of authority, (2) aggressive assimilation: negotiating relationships with peers, and (3) nonassertive separation: the convergence of negotiating relationships of authority and with peers. It is my hope that my story expands the awareness and conversation among and within academia regarding the influence that dominant cultural groups, norms, and labels have on the experience of adolescence living with TS as it relates to educational experiences. Keywords: Autoethnography, Co-Cultural Theory, Tourette Syndrome, Bullying, Identity, Disability, Education, Discrimination, Adolescence

“Beyond equal rights and due process, 'recognition is not just a courtesy we owe people. It is a vital human need….Nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being” (Christians, 2007, p. 442)

Within our society, one dominant group (that of European-American heterosexual middle-or-upper class males) has acquired status and power in our societal institutions (i.e., political, corporate, religious, educational, and legal institutions) overtime, which results in the culture privileging the worldview of this dominant group, and in turn makes other groups within our society marginalized within these major societal structures (Orbe, 1998a, p. 2). This results in nonrecognition for the marginalized groups and silences their voice. If recognition is a “vital human need” that may provide respect, opportunity, liberation or freedom (Christians, 2007), then it is important for marginalized members in society to be recognized by the dominant culture, especially within educational institutions. The emphasis placed on recognition within educational institutions is intended to show how the dominant culture can impact the communicative practices, wellbeing, learning, and bullying of marginalized members within their public schooling experience. The social paradigm of disability maintains “disability is a product of the intersection of individual characteristics (e.g., conditions or impairments, functional status, or personal and socioeconomic qualities) and characteristics of the natural, built, cultural, and social environments” (U.S. Department of Education & Rehabilitation Research, 2009, p. 2). Disability is a construct that finds its meaning within a social and cultural context that is privileged by the dominant group (Albrecht, Seelman, & Bury, 2002), especially within educational structures and institutions.

A recent Los Angeles Times article about undiagnosed disabilities turning into problems for students highlights a story of a teenager having difficulty in school with learning, behavior,
and bullying living with Tourette Syndrome, also known as Tourette’s or TS (Buffa, 2012). Throughout the boy’s educational experience, he had behavior and learning issues that were ignored by the school administrators and teachers, which resulted in bullying, poor academics, suspension for threatening to blow up the school, and eventually an attempt to commit suicide. It was not until he was seventeen years old that he was diagnosed with TS, Obsessive Compulsive Disorder (OCD), and Attention Deficit Hyper Disorder (ADHD). Buffa (2012) reports that the delay in diagnosis contributed to years of conflicts with classmates and teachers. Buffa explained that children with disabilities, diagnosed or undiagnosed, are easy targets for other kids (Buffa, 2012). This story highlights the importance of educating school leaders and teachers on the influence TS may have on a student’s educational experiences. It also sheds light on the negative impact that being undiagnosed with TS may have for students. However, what is left unknown are the communicative behaviors that students with TS use when experiencing bullying and other social interactions within their schools. Understanding how students with disabilities and/or mental health diagnoses experience, communicate, and deal with bullying, social interactions, and other related issues within public schools is critical if policy, pedagogical practices, and interventions are to be effective. Specifically, understanding how students with Tourette Syndrome (TS) negotiate their identity, communicative practices, and schooling experience is vital since Tourette’s is often overlooked. Little is understood about TS, characterized by sudden jerking movements and uncontrollable tics and vocalizations, despite that fact that three of every 1,000 children in the United States live with it (Centers for Disease Control and Prevention, 2009).

In this study, I explore this issue of recognition and nonrecognition further by providing a personal and autoethnographic account of my experiences living with TS, OCD, and ADHD, and negotiating the communicative practices employed within my public school experience using co-cultural theory (CCT) as the theoretical framework. In doing so, I seek to encourage teachers, social workers, educational psychologists and other professionals who deal with students living with TS to consider how their power and influence may hinder the communicative practices employed and educational and social experiences of these students in their care. Moreover, I hope to expand the research on co-cultural theory by attempting to understand how students with TS may negotiate their communicative behaviors within an educational setting, and also apply autoethnography to CCT when analyzing the communicative experiences of those in the margins. First, I begin by providing the context of when I was first diagnosed with the disorders to set the premise for this study. Second, I review previous research that explores the influence and impact of TS on individuals living with it, while also defining and discussing previous research that utilized autoethnography as the methodology and CCT as the theoretical framework. Third, I provide three narrative accounts (that take place during fifth grade) of my experiences living with TS and the communicative practices employed within my public school resulting in response to the power and influence of dominant group members. I explain how I negotiated with figures of authority, socially with my peers, and the convergence of negotiating with authority figures and my peers while providing a co-cultural analysis for each. Finally, I explain my findings and discuss the direction of future research. Even though I knew there were other people with TS out there, there were none at my school. I was learning and responding simultaneously to the TS co-cultural group.

The Diagnosis

I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me? It is amazing how drastically life can change within two months. Finishing fourth grade on top academically and socially was my biggest accomplishment of my 10-year
life. Receiving the highest honors all year and gaining in popularity, I knew I was the man, and confidence radiated from my smile. I had never been this happy, I was looking forward to a fun-filled summer of camping, playing hide-and-seek, staying up late and having my 11\textsuperscript{th} birthday! Little did I know that this summer was not the typical adventurous summer of the past that I had come to love. By the end of the summer, I would never be the same. Eleven years old, 50 pounds heavier, doped up on eight different medications and diagnosed with TS was my summer experience. I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me? This NOW became my reality.


MOM: JUNIOR, I DON’T KNOW WHAT TO DO! WHAT’S WRONG?!?!

Not knowing what else to do, my mother frantically ran around the house looking for the phone book to call my doctor. I, however, continued crying while simultaneously making weird noises that reminded me of Chewbacca. Nevertheless, while my mother was on the phone with my doctor, I started flapping and swirling my arms around like a fish out of water while squirming around the living room.


MOM (on the phone): Hello, this is Bettyann Congdon, and I need to schedule an emergency appointment. My son, Mark Congdon, needs to see his doctor right away. He’s running around the house flapping and swirling his arms and making weird noises. I don’t know what’s wrong and he can’t stop!

NURSE (on the phone): Ok, Ma’am, we just had a cancelation for 2:30, can you get here in 10 minutes?

MOM (on the phone): YES! We’re on our way!

As soon as my mother hung-up the phone, the weird noises and movements stopped. That’s the crazy thing about this; it was just within the past week that this started occurring more frequently. Throughout the past year I would make some of these weird noises, but I didn’t think anything of it nor did my family, friends or teachers, as it did not seem like a problem. I never knew when I would just burst out in uncontrollable movements and sounds or how long they would last. I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me? After going to three different doctors in a period of two weeks who were clueless, we finally discovered a medical professional who had answers.

DR. CADMAN (to my Mom & me): After talking with you both and Mark’s other doctors, I believe Mark is experiencing tics and has Tourette Syndrome.

I look up at my Mom scared, confused and not knowing what tics or Tourette Syndrome are, hoping she does.
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MOM: Okay (pause). What are tics, and what is Tourette Syndrome? Is it curable or contagious? How did Junior get it? Will he be okay?

*My Mom and I sit engaged with an uncertain look in our eyes as we wait for the doctor to answer my Mom’s questions.*

DR. CADMAN: Mark will be fine. It is not contagious, and there is no cure for it, but we have medication to help with his Tourette’s. Tourette Syndrome, also called TS, is a neurological disorder that is characterized by repetitive, stereotyped, involuntary movements and vocalizations called tics, which are the movements and sounds that Mark is doing. There are many different types of tics, which Mark may or may not experience or develop. Eye blinking, shoulder shrugging, head or shoulder jerking, repetitive throat-clearing, sniffing, or grunting sounds are a few non-severe examples. There are more complex types of motor tics, but I will give you some information to take home explaining more thoroughly what TS and tics are. TS is also thought to be hereditary, so someone from you or your husband’s family may have had or currently has TS, and Mark must’ve inherited it. Most people with TS experience more severe symptoms in their childhood and teens, and as they get older the symptoms start to decrease. This is probably why Mark is experiencing the symptoms now. I know this is a lot to take in, and you may be worried, but most people with TS live a normal and healthy life. A very small percentage of people have severe symptoms of TS, and currently, Mark is not experiencing those severe symptoms.

MOM: I’m not aware of any family members that have this, but I’m relieved that Junior will be okay. Junior, do you have any questions? (I then rush in with a concerned tone in my voice).

ME: Will I need to take medicine for the rest of my life? Will I be able to go to school?

DR. CADMAN: We do not know yet if you will need to take medicine for the rest of your life. It’s way too early to tell and depends on the severity of symptoms that you’re experiencing. You will be able to go to school, and should be fine. (Dr. Cadman turns to my Mom) I want you to be aware that tics become usually worse with excitement or anxiety, and certain physical experiences can trigger or worsen tics such as hearing another person sniff or clearing their throat or even wearing a tight-collared shirt. This is NOT to say that this will happen to Mark, but I just want you to be aware. I want to schedule another appointment before Mark goes back to school in August to check in and see how everything is going. I wrote some prescriptions for Mark to take that are at the checkout counter. I recommend contacting Mark’s school so that they are aware of Mark’s diagnoses, too.

Two months later as the summer came to a close, I looked in the mirror and did not even recognize myself. My eyes were dark, so dark they looked empty, sad and alone. *Who am I? Why did this happen?* The new school year started in less than a week, and I was so fat, 50 pounds heavier to be exact. That fun and adventurous summer of camping, hide-and-seek and an awesome 11th birthday that I looked forward to two months ago were only a figment of my
imagination. My mind was racing, and I was having so many negative self-thoughts, and thought to myself: *Those stupid medications caused me to gain weight and develop depression as a side effect. WOW! So much for helping with the Tourette’s. I have bigger problems to deal with, literally. I can’t go to school like this. Will I always feel and be like this? Will my Tourette’s impact my grades? Will this ever end or will this be my reality forever? I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me?*

**Finding the Gap**

Many studies have explored the difficulties of TS in the educational setting with academic and behavioral interventions (Abwender et al., 1996; Chaturvedi, Gartin, & Murdick, 2011; Comings, Himes, & Comings, 1990; Conelea et al., 2011; Kurlan et al., 1991; Packer, 2005; Shady, Fulton, & Chamption, 1988; Stefl & Ruven, 1985; Turton & Rayner, 2007), and on the perceived impact of adolescents living with TS on the self and on relationships with others (Wadman, Tischler, & Jackson, 2013). Furthermore, multiple studies have examined the longitudinal sensitivity of psychosocial stress of individuals living with TS, OCD, and ADHD (Bornstein, 1990; Chappell et al., 1994; Findley et al., 2003; Hoekstra et al., 2004; Lin et al., 2007; Silva, Munoz, Barickman, & Friedhoff, 1995; Surwillo, Shafii, & Barrett, 1978; Thomsen, 1995), and on studying the language skills of students with TS (Legg et al., 2004). A number of studies have evaluated the effects of bullying and teasing in social situations with their peers (Bawden, 1998; Boudjouk et al., 2000; Cutler et al., 2009; Debes et al. 2010; Friedrich, Morgan, & Devine, 1996; Stokes et al., 1991; Storch et al., 2007; Zinner et al., 2011), and on the prevalence of depression, anxiety, stuttering, dyslexia, and phobias with people having TS (Comings, 1990). There is, however, little research that discusses TS from a personal point of view. In order to understand how the dominant culture influences the reality and communicative practices of those in marginalized groups, the analysis of various levels and influences of the dominant power structures is needed. Co-cultural theory recognizes that the dominant culture silences those who are considered “outsiders” to the dominant group, and gives voice to those “outsiders,” who are marginalized (Orbe 1998a; Orbe, 1998b). CCT explores how these power structures of the dominant group influence the communicative practices of those in the margins.

**Giving Voice: Setting the Stage**

Autoethnography is a “research method that uses personal experience in order to understand and critique cultural experiences” (Adams, 2012, p. 1). Autoethnographers write in the first-person while looking back and forth “first through an ethnographic wide-angle lens, focusing outward on social and cultural aspect of their personal experience; then look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations” (Ellis & Bochner, 2000, p. 739). Adams (2012) describes how “critically-orientated researchers expand on this purpose by using personal experience to illustrate, interrogate, and disrupt lived instances of hegemony, oppression, cultural inadequacies, and other kinds of harm” (p. 2). Framing this study as “critically-orientated” allows me, as the researcher, to analyze and unpack the power dynamics of the dominant cultural group within my public school. Merrill and West (2009) have examined how biographical autoethnographic research helps raise awareness of experiences that are often overlooked including those with learning disabilities, woman’s experiences of higher education and other marginalized groups in the educational environment. Using this view of autoethnography as my methodological framework enables me to give voice to the traumatic and tragic events that are often neglected by traditional research methods (p. 11), with the intent of disrupting traditional norms of
representation that may result in the breaking of “harmful cultural silences about taboo topics” (Adams, 2012, p. 10). A retrospective investigation of my own research allows me to make meaningful connections between theory and practice (Watt, 2007). Essentially, my study is a combination of evocative autoethnography, aimed at delving into the depths of my experiences, followed by an analytic approach driven by CCT.

Using the critically orientated view of autoethnography, I use my memory, reflexivity, and storytelling of my personal experiences as a student to describe and call attention to how dominant structures and individuals within the public school system negatively influenced the communicative practices I employed. I was marginalized within my school setting as a student with TS. Marginalization influenced the communicative practices I used and how I responded to it. Reflexivity allows me to analyze the process that occurred. Glesne and Peshkin (1992) explain that reflexivity is crucial as a means to continuously work on becoming a better researcher; a journal provides a focal point for this activity.

Using systematic sociological introspection (Ellis, 1991), I have written reflective narratives and free-wrote to myself on my experiences of coping with TS in the public school setting. Systematic sociological introspection allows the researcher to look into the process of “thinking about thinking and feeling about feeling” in a focused manner in order to inspect and analyze the lived experiences of the self (p. 32). Ellis (1991) discusses that “introspection can be accomplished in dialogue with self, and represented in the form of fieldnotes, or narratives: or it can be accomplished in dialogue with others” (p. 32). In constructing this analysis of the autoethnographic process, I reviewed the data written and identified themes pertaining to my co-cultural experiences (Ellis, 1991; Miles, Huberman, & Saldana, 2013; Richardson & St. Pierre, 2008). The analysis process for this paper involved me reading and coding the journal entries, free-writes, and narratives that I wrote. I then generated themes, particularly paying close attention to the reactions and reflections of my experience in my public school, and analyzed them using co-cultural theory. Lastly, to reassure the trustworthiness of my interpretations and findings, I consulted with two communication experts in autoethnography and CCT, and a peer editor who reviewed my manuscripts. During this process, the findings were further refined and supported for dependability (Miles, Huberman, & Saldana, 2013).

I have used my notes from theses journals to illustrate how the dominant power dynamics within the school setting influenced the communicative practices I employed and negotiated within my public schooling experiences. To protect the identities of those I discuss in my study, pseudonyms have been assigned in my narratives. The narratives provide links, connections, coherences and meanings to help make sense of and to further understand the experiences I have encountered in my public education (Silverman 2010). The narratives also provide the field of experiences through which I carry out the autoethnographic exploration of my TS, helping me examine social actions within an education context from a co-cultural point of view and helping me probe my problematic experiences (Goodson & Sykes 2001). Thus, the researcher’s personal experience becomes important in illuminating the phenomenon under study.

**Co-cultural Theory**

Co-cultural theory describes and classifies the communication orientations and practices enacted by marginalized groups in response to perceived discriminatory and oppressive acts from dominant group members (Orbe, 1998a, 1998b). Orbe (1998a, 1998b) developed CCT and uses a phenomenological approach that seeks to expose the “commonalities among co-cultural group members as they function in dominant society while substantiating the vast diversity of differences between and among groups” (Orbe, 1998a, p. 134). A phenomenological approach is appropriate for this study because it addresses the
meanings and perspectives of the co-cultural group members. The basic premise of CCT is to provide insights into how people traditionally situated on the margins of society (people of color, women, lesbians/gays/bisexuals, and individuals from a lower socio-economic status, etc.) communicate within the dominant societal structures (Orbe, 1998b, p. 1). CCT recognizes that to confront the oppressive dominant structures (educational, legal, government, corporations, religious) and to achieve any measure of success within these dominant structures in the society, co-cultural group members embrace certain communication orientations while functioning within these dominant communicative structures (Orbe, 1998b, p. 7).

CCT explains that enacted by co-cultural group members that influence the communication orientations, three primary outcomes, which also include specific communication strategies that connect to the overall strategies such as avoiding, mirroring, self-ridiculing, educating others, and censoring self among others, are: (1) assimilation, which attempts to eliminate cultural differences, (2) accommodation, which attempts to promote the collaborative strength and work with people from the dominant culture, (3) separation, which attempts to reject the dominant culture. These outcomes have three communication approaches that include: (1) nonassertive behavior, which involves suppressed behaviors and actions, and contemplates the needs of others before oneself, (2) assertive behavior, which comprises of expressive communication behaviors that ponder the needs of oneself and others, or (3) aggressive behavior, which includes more controlling and hurtful actions towards others (Orbe, 1998a, 1998b; Orbe & Roberts, 2012; Orbe & Spellers, 2005). The preferred outcomes are combined with the communication approaches to get the communication orientation enacted by the co-cultural group member (Orbe, 1998a). Orbe (1998a, 1998b, 2012) explains that the communication orientations are influenced by six key communicative practices: preferred outcome, field of experience, situational context, abilities, perceived costs and benefits, and communication approach. All six factors are mutually dependent and represent, when taken together, a holistic framework for understanding the co-cultural decisions enacted. Utilizing these factors, co-cultural group members continuously adjust and negotiate the communication practices employed based on their environment and the context within the dominant culture (Orbe, 1998a, pp. 88-89).

Numerous researchers have applied co-cultural theory to study an assortment of underrepresented groups and contexts. Such studies include investigating the power dynamics within the workplace, universities, everyday lived experiences of co-cultural group members, and policies’ influences on these groups. The completed studies explored co-cultural groups within the university setting including first generation college students, African Americans, international students, and students who have experienced discrimination based on race, sexual orientation, or age (Camara & Orbe, 2010; Glenn & Johnson, 2012; Orbe, 2004; Orbe & Groscurth, 2004; Urban & Orbe, 2007). Scholars have also used CCT within the workplace, specifically looking at the organizational socialization of people with disabilities (Cohen & Avanzino, 2010). Research analyzing the everyday lived experiences of co-cultural group members such as gay/lesbian/bisexual (Camara, Katznelson, Hildebrandt-Sterling, & Parker, 2012), individuals from lower socioeconomic classes (Orbe, 1996), and gang members (Towns, 2007) has also been conducted. Moreover, another study has looked specifically at how current school reform policies have failed educational institutions when dealing with issues of diversity (Morrissey, 2008). However, there are no studies currently that have utilized a co-cultural theoretical model investigating the communicative practices of students with TS in a public school environment.

Despite CCT being utilized to give voice to those co-cultural group members who are marginalized within various contexts and settings, no studies have been completed from the personal view of a co-cultural group member. This study applies CCT in a new setting, specifically looking at co-cultural group members with a disability within a public school while
also employing autoethnography. This study explores how I utilized assimilation strategies, while weighing the costs and rewards during my adolescence, when it comes to interaction with the dominant culture within my public school in order to “fit in” and not be bullied. Utilizing autoethnography as my methodology allows the co-cultural communication orientations that I partook in as a person with TS, OCD, and ADHD within the public school setting to be explored.

**Narrative 1: Negotiating Relationships of Authority as a Student**

**First Day of Fifth Grade**

This narrative took place during my fifth grade year, and described the relationship and power dynamics that I experienced with my teacher.

_I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me?_ Entering my fifth grade classroom during the fall of 1996 was a scary moment for me because I did not know what to expect with my TS and how my teacher would perceive me. My fifth grade teacher, Ms. Washington, was new at our school and I did not know anything about her. She was an older teacher in her mid to late 50’s with short curly brown hair, and big thick glasses. My mother wrote a letter to Ms. Washington explaining how I was diagnosed with TS over the summer and wanted to request a meeting. As I gave the letter to Ms. Washington, she sarcastically scolded me.

**MS. WASHINGTON:** A parent letter already on the first day of school. What could possibly be wrong with you?

**ME:** My mom wanted me to give this to you telling you about how I was diagnosed with Tourette Syndrome over the summer.

**MS. WASHINGTON:** Tourette what? Sit down and I will read it later.

As I sat down to the desk with my nametag on it, I felt tears building up in my eyes. I did not want to be here. I wanted to go home. I had an inkling that this was going to be a bad year because I already did not like the interactions I had with my teacher. Her not knowing what TS was only made me feel even more abnormal and like a freak. _I thought to myself: get it together Mark. You cannot let anyone see you cry, especially the teacher. I need to smile and look like I am doing what I am supposed to. It will be okay; it will be okay, just smile and look happy._

**The Tic-Tic-Ticking Time Bomb**

It was midpoint during the first semester of fifth grade and I was not doing well academically. Even though my Mom met with Ms. Washington and told her about my TS, Ms. Washington still thought that my tics were controllable and that I was just not focusing and studying hard enough. Ms. Washington always would tell my Mom, “Mark is an average C student. He’s doing fine, but just needs to study more and be focused in class if he wants to bring up his grades.” Although I was not failing, I went from an honors student with all A’s in the fourth grade to a C student struggling to keep up with my more average “normal” peers. My predictions about Ms. Washington were true. As a child, I felt that she did not like me, and I did not like her. She was a mean old lady whom I felt did not care about me as a student. Her actions proved this, especially when we would read aloud during reading class.
MS. WASHINGTON: Mark please read the next paragraph.

ME: ummmm… Tic-Tic-Tic, cough, cough, urgh, urgh Ms. Washington I…I…I… lost my place. Where are we again? Tic-Tic-Tic, cough, cough, urgh, urgh (students laughing in the background and Ms. Washington not saying anything)

MS. WASHINGTON: Mark you’re always losing your spot. No wonder why you’re struggling in reading. Just focus and stop making those noises and maybe you won’t get lost. You better start paying attention or I will have to call home. We are on page 105 third paragraph down. Did you find it?

(I hated when she called me out like that. She did it all the time, and it only made me nervous to participate. I always have a hard time focusing, and she knows that. My Mom told her. I hate this class. It will be okay, just smile, be nice, and STAY focused Mark).

MARK: Yes, I got it. Tic-Tic-Tic, cough, cough, urgh, urgh Thank you… (Students continue to laugh in the background)

I felt stupid and did not enjoy school like I used to. I never spoke out and always did what I was told. I was a respectful student even though I wanted to cuss Ms. Washington out, especially when she would give back our vocabulary tests.

MS. WASHINGTON: Class I have graded your unit 4 vocabulary tests and overall everyone has done well with the exception of a few students. As you continue to work in your reading workbook, I will call your name to come up to my desk to pick up your test. If you have any questions, you can ask me then. Matt, please come up first.

(I hated this part of class more than anything because Ms. Washington would always bash my work. I began to do my motor tics: Tic-Tic-Tic, cough, cough, urgh, urgh while students laughed at me)

MARK: Hi Ms. Washington how did I do? (I continued to do my motor tics, but now started flapping my arms in the air, which was the first time this occurred in class). Tic-Tic-Tic, cough, cough, urgh (swirl, swap, spat, flap, swirl, swap, spat, flap, swirl, swap, spat, flap)  

MS. WASHINGTON: Mark what are you doing? Are you trying to hit me? Stop that!

MARK: Tic-Tic-Tic, cough, cough, urgh (swirl, swap, spat, flap, swirl, swap, spat, flap, swirl, swap, spat, flap) I’m sorry. I can’t stop…these are my…my…my tics… (students laughing in the background)
MS. WASHINGTON: Well you’ve never done this before. Stop showing off. Your lack of focus is contributing to your failing grades. You were one of the few students who failed this test. Why haven’t you been studying?

MARK: *(my nonverbal tics stopped while just my verbal tics continued)* Tic-Tic, cough, cough, urgh, urgh... I’m sorry Ms. Washington I have studied but I am still not getting it. Do you offer tutoring after school or during recess so I can get some extra help?

MS. WASHINGTON: Mark, I know you have not been studying. Your behaviors and academics proves this. I will not take time out of my busy day to tutor you when you’re just being lazy and showing off.

MARK: *(my tics have finally stopped)* Okay, I understand. I just want to do well like I did last year.

MS. WASHINGTON: Mark you need to stop living in the past. This is not last year and you are not the perfect student you claim to be. You’re not perfect and never will be. If you study, pay attention in class, and stop goofing off you will do fine.

MARK: Okay. Thank you.

As I sat back down, tears began falling from my eyes. I never felt so humiliated in my life. I hated school. I hated Ms. Washington. I hated my peers. No matter how respectful I was and how hard I tried to focus, I was still struggling. I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me?

As fifth grade continued, my grades did not improve. Despite several meetings between my parents and school officials, nothing was put into place to address the educational plunges that had occurred. Multiple doctor visits and psychological assessments by a private psychologist did not convince school officials that my TS was a factor in my academics although my tics were not always present. I hated these meetings because nothing ever came out of it, except for reaffirming my loneliness in this god-awful school.

I did my best to be respectful and quiet with my teacher. No matter how hard I tried to be nice, smile, and do as I was told, I would still be lost and could not keep up with my peers. Ms. Washington finally agreed to tutor me. Unfortunately, I stopped going because she would just ridicule me. She was the ultimate bully because my peers would feed off what she did in class. From the school’s perspectives, nothing was wrong. I even went to counseling, which proved to be a failure since nothing at the school changed. Everything that I felt only seemed to be confirmed with everything that I did, that I was a stupid freak who is not normal. *I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me?*

**Digging Deeper**

When negotiating relationships of authority with my teacher and deciding how to communicate my identity with my teacher, the communication strategy and the preferred outcome I selected were nonassertive assimilation. Nonassertive assimilation orientation deals with how a marginalized member tries to avoid conflicts with dominant group members where co-cultural group members seek to be regarded as people whose goal is focused on social
standing or on the production of the task at hand (Orbe, 1998a, p. 111). This may enhance a co-cultural group member’s ability to participate within the boundaries of the dominant structure. However, co-cultural group members may experience negative self-concepts resulting from this, which only reinforces the dominant culture’s social and institutional power (Orbe, 1998a, p. 111).

I believed it was best to be respectful and not to engage in arguments with my teacher. If I engaged in a more confrontational manner, my teacher would only embarrass and bully me. She would further develop a bias against me, resulting in potentially lowering my academic performance. When communicating with my teacher, I primarily used censoring self and developing positive face when striving to assimilate into the classroom learning environment. Censoring self is a strategy where co-cultural group members remain silent when comments from dominant group members are inappropriate, indirectly insulting, or offensive (Orbe, 1998a, p. 16). I was often guarded with what I said because I feared that if I spoke up, it would negatively impact the relationship with my teacher. This could lead to my academics being further hindered. I did not want to take this chance or risk being written up for being disrespectful.

I often coupled censoring self with the strategy of developing positive face to distance myself from being defined by my Tourette’s and to focus on the tasks involved within my education. Developing positive face involves assuming a more courteous communicator stance in which one is more respectful and polite to the dominant group members (Orbe, 1998a, p. 16). By using manners such as “thank you,” and not questioning the authority of my teacher when she accused me of not studying, I utilized these communicative practices to draw attention away from my tics. I did not want to be defined by more negative behaviors and to reinforce the belief that my teacher had regarding my inappropriate behaviors and low academic performance. I hoped that by being respectful and appearing positive, my teacher would start to believe what I said about studying, and not understanding the material.

My teacher had the authority and power within the classroom. I did not have any power or anyone to turn to with power that would help or believe me. I felt truly deserted as I did not think anyone at the school would believe that my teacher was bullying and harassing me in class. What evidence did I have except for my word and feeling? By being an educator for over 20 years, my teacher, on the other hand, had all the credibility and proof to suggest that I just needed to study more. I was not able to advocate for myself because of the obvious lack of power and credibility that I had. I evaluated the benefits of standing up for myself or keeping quiet, and felt that I could not rock the boat; therefore, being silent was my only option that was in my control. Unfortunately, this contributed to my negative self-thoughts. I felt as if something was wrong with me since I did not feel like anyone would believe me. This means that it must have been me. I studied more, which did not help improve my grades. I was polite to my teacher, which did not help with her harassing and embarrassing me in class. This solidified further my belief that I was to blame and that something was wrong with me.

Student misbehaviors may cause teachers to further believe that the student cannot achieve academically, thus further lowering expectations when teaching and interacting with these students (see Calabrese, Hummel, & San Martin, 2007). It is also suggested that at-risk students are statistically more likely than others to fail academically and lack self-esteem necessary to have meaningful options in the areas of culture, civic affairs, work, leisure, and inter/intra personal relationships (Sagor & Cox, 2004). Even though I was not failing, I felt that if I responded more aggressively or assertively by defending myself, I would be further marginalized and stereotyped as a student with severe behavioral problems who did not want to learn. Being polite and respectful when communicating were, therefore, my only solution. Because of this, I developed a negative self-concept and thought that I was abnormal and a freak. I did not receive supports or sincerity from my teacher as when I was not diagnosed with
Tourette’s. This once again inscribed in my brain the idea of me being a freak and not trying hard enough as well as reinforced the power that my teacher had over me when communicating. Because being taught to be subordinate to the teachers, school officials, and educators who manage the school, students are not allowed to question their decisions, authority, or power (Giroux, 2011). Ms. Washington expected her students not to question her authority. This culture of authoritarianism was also reinforced in the school environment at my elementary school. My teacher abused power by being very authoritative and using coercive methods – the application of negative influences (Molm, 1997). She utilized fear tactics that were psychologically detrimental to me, causing me to suffer academically and socially as exhibited from the narrative.

The dominant institutional structure within the school limited my voice and influenced how I responded to the abuses of power by my teacher. If I stood up and defended myself, I would get into trouble by my teacher and/or those who managed my school. Because of my self-censorship (and not standing up to my teacher), the bullying and harassment continued to take place. I was, indeed, in a lose-lose situation, where the only appropriate thing I could do was to continue keeping quiet, and hoping things would change.

**Narrative 2: Negotiating Relationships with Peers as a Student**

**Bullying During School**

This narrative took place during fifth grade as well, and described the relationship and power dynamics that I experienced with my peers during school and extracurricular activities. I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me? In the fifth and sixth grades, I would often spend recess alone on the playground. My peers consistently bullied me, which was the activity of repeated, aggressive behavior intended to hurt another person, physically or mentally to gain power over another person (Bennett, 2006). They bullied me because of the tics I would do and the weight that I gained. I even earned a nickname that would stick with me until I graduated high school: Bubby. However, I did not want to be alone. I wanted to be a “normal” fifth and sixth grader and did everything I could to “fit-in.” I embraced this nickname and allowed my peers to call me this, but this did little to limit the bullying.

MARK: Seth, can I play basketball with you and your friends for class? Tic-Tic-Tic, cough, cough, urgh, urgh…

SETH: Sure, BUBBY, but are you able to play? Those noises you make are weird and distracting from the game.

MARK: Tic-Tic-Tic, cough, cough, urgh, urgh…I can make baskets!

SETH: Prove it, BUBBY!

Seth then threw the basketball at me forcefully as if challenging me to a match. I got the ball, shot, and missed. Seth and his friends laughed. I began to walk away looking to play with someone else.

SETH: Hey, BUBBY, look over here you FREAK!
As I looked over to where Seth was standing in the gym, I saw a ball swooshing towards my face. However, I had little time to move and react. The ball smacks my face with a loud THUD.

MARK: OUHH!!! Tic-Tic-Tic, cough, cough, urgh, urgh…Seth that hurt! I’m telling.

I turned around and ran towards where the gym teacher, Mr. Baber, was located to get away from Seth and his goonies while they laughed hysterically at my pain and misery.

MARK: Mr. Baber… Tic-Tic-Tic, cough, cough, urgh, urgh…Seth threw a basketball at my head on purpose.

MR. Baber: What? Are you sure it was on purpose? Let me go talk to them.

As we walked towards Seth and his friends, they played basketball like nothing had happened.

MR. Baber: Seth did you throw a basketball at Mark’s head?

SETH: No, Mr. Baber. I made a shot and missed. The ball bounced off the backboard and hit Mark in the face. I told him I was sorry, but he ran away saying he was telling.

Mr. Baber turned to Seth’s friends and asked if this was what really happened, and they confirmed what Seth said.

MARK: They are lying! Tic-Tic-Tic, cough, cough, urgh, urgh…Seth threw the ball at my head!

MR. Baber: Mark, they all said it was an accident. Go over to the other basketball hoop and finish gym class over there. Make sure to watch for flying balls this time so you don’t get injured.

As I walked over to another hoop, I became frustrated and angry. If only I would have made that basket, this would have never happened, and I would be playing basketball now. I hated school. I hated my peers. I hated myself. I was so stupid.

Bullying During Extracurricular Activities

Despite being called Bubby and being ridiculed at during class with Ms. Washington, I joined the wrestling team and Little League baseball team with hopes of establishing a positive presence in sports. I prayed that it would take the focus off of my TS. However, this failed and did little to stop the bullying. The bullying was reinforced from academics during classes to my extracurricular activities. My tics ended up being severe while playing baseball and interfered with my ability to focus and perform athletically at the level of my peers.

MARK: Tic-Tic-Tic, cough, cough, urgh, urgh, jump-smack, jump-smack, jump-smack…Oh crap the ball’s coming towards me…Tic-Tic-Tic, cough, cough, urgh, urgh, jump-smack, jump-smack, jump-smack…
I put my glove in the air and ran towards the ball, but missed it like I always did. I was the right fielder for our Little League team. I developed a new tic when I would play baseball. While making the traditional noises that I usually did, I also would jump up and down and smack my glove on the ground while out in the outfield. For some reasons, I did this the most just when the batter was about to bat. This proved to be a problem as the ball would always get hit towards me, and I would always miss it because of doing my tics.

COACH: MARKKKK! Get up and stop jumping up and down! You NEED to focus! Get in the correct spot behind the first baseman!

MARK: Tic-Tic-Tic, cough, cough, urgh, urgh, jump-smack, jump-smack, jump-smack...sorry coach! I can’t help it. I will try to focus. Tic-Tic-Tic, cough, cough, urgh, urgh, jump-smack, jump-smack, jump-smack

However, no matter how hard I would try to focus or not do my tics, I was never able to stop. This not only caused problems with winning games, but my teammates (some were peers in my class and others were not) would bully me during practice and the games and would not be reprimanded by the coach.

JOSH: Mark stop being a freak and focus! You’re going to make us lose the game!

Josh was the pitcher of our team, a sixth grader, and was a well-respected leader. He was the assistant coach’s son and considered one of the best players on our team. My teammates all looked up to him and followed in pursuit of whatever he did, including bullying me.

CHRIS: Yea, BUBBY, if we lose the game, it will be your fault! Pay attention you FREAK!

Chris was the first baseman and also one of the best players on our team. He was also in my class with Ms. Washington and would bully me during school as well.

No matter what I did I could not fit in and do well. I failed academically. I failed at sports, and I was a failure with my peers. None of the authority figures in school or in the extracurricular activities would help me or stand up for me. I was all alone. I hated school. I hated sports. I hated my peers. I hated myself. I was a freak. I was abnormal. I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me?

Digging Deeper

When negotiating relationships with my peers, and deciding how to communicate my identity, the communication orientation and preferred outcome I selected were aggressive assimilation. Aggressive assimilation is when a co-cultural group member places great efforts on fitting in by taking a determined stance to be seen as one of the dominant group members (Orbe, 1998a, p. 112). I wanted to be seen as normal by my peers so the bullying would stop. Also, I would not be identified solely by my Tourette’s. I would get the courage to seek out acceptance by my peers through asking to be a part of their teams in gym class and joining the wrestling team and Little League. I was worried that if I isolated myself and did not try to assimilate within the school and extracurricular activities, the bullying would continue and only
would get worse. I needed to do something, and felt this was the only thing I could do that was within my control.

When communicating with my peers socially, I primarily used strategic distancing, mirroring, and dissociating. Strategic distancing is when co-cultural group members avoid association with other co-cultural group members so that they are perceived as an individual (Orbe, 1998a, p. 16). Although there were no other students or faculty at my school who had TS, there were support groups within my state for students with TS and who were bullied that my mother encouraged me to join, but I refused. I did not want to be associated with my co-cultural group. I wanted to be normal. I thought by aggressively trying to assimilate with my peers, I would be seen as an individual and not as someone with TS. I wanted the bullying and the tics to stop. I was afraid that if I went to these support groups, my tics would increase along with the bullying. Not acknowledging it and refusing to go to these support groups helped me think that I was an individual who was in control of what I wanted to do.

CCT describes that a benefit to aggressively assimilating is that the dominant culture may see a co-cultural group member as an individual rather than being identified as with their particular group, while a downside is that other co-cultural group members would see this as selling out (Orbe, 1998a). However, this did not occur. I never met any other member of my co-cultural group because no other students with TS attended my school. Since involuntary audible and motor tics are what contribute to TS, I could not escape my co-cultural identity, no matter how hard I tried to aggressively assimilate. This made me feel even more abnormal and alone.

Mirroring is when a co-cultural group member adopts dominant codes so that their cultural identity is less visible (Orbe, 1998a, p. 16). By joining the wrestling and baseball teams, I tried to become an athlete, hoping that being a part of this dominant group would disassociate my identity with my co-cultural group. I would be seen as an athlete. This was not the case. The bullying became worse as I was now being bullied by classmates and teammates. My peers continued to associate me with having TS and not as an athlete. I knew that athletes were well respected in my school and had power and influence because they were the ‘popular students’ who were not bullied. I thought joining the wrestling and Little League teams depicted me as an athlete instead of someone with TS. Unfortunately, my ability to be on equal footing with my peers did not work. Through trial and error, I thought that I would effectively communicate with my peers so that the bullying would cease or be reduced. My ability to enact the communication strategies was limited because TS is directly connected to my verbal and nonverbal communication through the tics.

Dissociating refers to the determined effort co-cultural group members make to avoid any connection with behaviors that are associated with a co-cultural group (Orbe, 1998a, p16). By seeking to join a group of popular students during gym class, trying to establish my nickname, Bubby, as a positive identity, and attempting to suppress tics while playing baseball, I was trying to distance myself from being associated with someone living with TS. I was not able to assimilate into the dominant group, regardless of my efforts, because the communicative practices of mirroring and dissociating were ineffective to deal with nonverbal and verbal behavior. I was experiencing “disability spread” where the dominant group members assumed that my TS was the defining characteristic of my identity, which resulted in their negative perception transferring the TS to other personal qualities of mine (Leisener & Mills, 1999). Rejection by the dominant group resulted in me being depressed and negatively reinforced many of the self-deprecating thoughts that I already had.

The difference between the power dynamics with my peers and authority figures at my school was the type of power that each had. Although my peers were students, they had referential power, which is the power or ability of individuals to attract others and build loyalty where a person can be admired because of specific personal traits (Tjosvold & Wisse, 2009).
The educators at my school had authoritative or coercive power. I could not be seen as an equal when trying to be an athlete; therefore, I was not admired for any of the skills or traits I brought to the team or the classroom. By handcapping myself via my TS identity, my peers asserted their power for bullying purposes.

Using these three strategies contributed to me further feeling isolated since I did not want to associate with other co-cultural group members and only wanted to identify with the dominant group. Due to being rejected by my peers and not having a support system with other co-cultural members who might share my experiences, I did not have anyone to talk to for help, understanding, or guidance with my situation.

**Narrative 3: Convergence of These Worlds**

This narrative focused on intrapersonal communication issues that I was experiencing. It described what resulted from the convergence that occurred with my teacher and my peers.

I'm scared, confused and feel like a freak. This is not normal, I am not normal. What's wrong with me? As I sat in my aunt's room visiting for the weekend, mentally preparing myself for what I was about to do, I realized how dimly lit and dark the room was; yet the walls looked so fresh and white. It was ironic how the lighting was so sad, subtle and lonely but the walls exerted hope, opportunity and cleanliness. Complete opposites of each other. I used to be so happy, hopeful and unpolluted just like the walls, but now I was depressed, in despair and clueless. Eleven years old and miserable. I reflected on myself: How did I get to this place I am in? I hate myself! I used to be happy. What happened? Will I feel better once I slice my wrist with these silver scissors? Will the pain end? Will I go to Hell? I'm already in Hell, so it's not like it matters. Will my teacher or peers care or even miss me? Probably not, they do not even recognize or acknowledge the pain I am going through with my TS. I'm not a star student. I'm forgettable. I'm an unintelligent mutant with a medical disorder. I'm a gross fat pig and no one can ever love someone as disgusting as me, and hell, I have no friends! All alone, that's me. I'm ready. As I sliced my wrist with the sharp silver scissors, ready to meet my maker, I reflected on the isolation and loneliness that I was feeling that resulted from being bullied and marginalized by my teacher and peers.

I ended up dropping out of Little League and wrestling because the bullying continued to run rampant in my school. At this moment, I decided to do my best to avoid my peers and others at my school. I was and felt alone. I did not want to be bothered by anyone associated with my school. I avoided everything and everyone.

This isolation contributed to the further decline of my academics. I no longer cared about school because no matter what I did to try to bring up my academics, nothing seemed to work. Ms. Washington continued to embarrass me in school. By the end of the third marking period in March, I had missed seventeen days of school. I would stay home and play sick so I could avoid what awaited me at school. This did not last very long, as my parents caught on to what I was doing and would force me to go to school. They did not understand how I felt or what I went through. I would think to myself, if they love me, why are they making me go to this hellish place? If they know it causes too much pain, why won’t they help me?

I felt like I was motionless in school, always sticking to myself and doing my best to avoid my bullies. I even skipped recess by going to the nurse’s office every day. After school I would go right back home. On the weekends, I stayed by myself, and never attended any school or community events. I isolated and shielded myself from everyone and everything. Because there were no other people or students living with TS at my school or in my community, I had no one to talk to. Although there was an advocacy group for people living with TS, it was located in Lancaster, Pennsylvania, over three hours from where I lived. Eventually, I could not take the isolation and loneliness anymore. I knew that the only way to
make the pain, suffering, and TS to go away was to end my life. I knew that was what I had to do.

As I finished slicing my wrist a second time, blood, lots of dark red blood, gushed out of my wrist, onto my arm and then onto the floor. Waiting. Waiting. Waiting. Still waiting...to be dead and for the pain to go away. Thirty minutes later, still not dead, just woozy from the loss of blood. What happened? Why am I not dead? Oh my god, I think I need a doctor. Forgetting I was not at home, I SHOUT-MOMMY! My Aunt rushed in to see what was wrong and saw the puddle of blood that had developed on the floor and SCREAMED! I’m scared, confused and feel like a freak. This is not normal, I am not normal. What’s wrong with me?

Digging Deeper

When dealing with the issues present within the school system the communication technique and preferred outcome I selected were nonassertive separation. Nonassertive separation is when co-cultural group members avoid interacting with dominant group members (Orbe, 1998a, p. 115). I could not reduce or stop my tics in and out of class, and could not convince my teacher that I had TS. I could not stop the bullying from occurring. As a result, I avoided everything and everyone at all costs. I used avoiding and maintaining barriers when trying to separate. Avoiding is maintaining a distance from dominant group members and reframing from events or settings where communication is likely to occur (Orbe, 1998a, p. 17). By quitting the Little League and wrestling teams, and not seeking out help with my academics, I avoided interactions with those at my school so that I would not be bullied, ridiculed, or humiliated.

Maintaining barriers is when co-cultural group members maintain a psychological distance from dominant group members through verbal and nonverbal cues (Orbe, 1998a, p. 17). By feeling motionless and isolating myself while in school, I ignored the bullying and discrimination from my peers and teachers. Bullying and placing negative labels on people, especially marginalized group members, may contribute to low self-esteem, feelings of being abnormal, hopelessness, lack of control of one’s own life or situation, self-loathing, and may even lead to suicide (Klomek et al., 2007; Sedikides, & Luke, 2007; Tucker-Ladd, 2009; van Zyl, Cronjé, & Payze, 2006; Young et al., 2012).

No matter how hard I tried to separate or isolate myself from the dominant group members within my school, the bullying and discrimination continued. Through trial and error, I adapted my communication and how I responded, yet nothing seemed to work. I then switched to nonassertive separation. In addition, the power dynamics of my teacher and peers worked together against me because I should have been able to go to my teacher to address the bullying from my peers that I was experiencing. I could not address the bullying because my teacher used her authoritative and coercive power to silence and marginalize me in the classroom. Ms. Washington did not support, care, or protect me from my peers because she was also bullying me.

Students can usually go to their teachers for protection and guidance from being insulted and harassed by their peers. Sadly, this was not the reality for me. I believed that I had no right to be on the sports teams because I held the team back. I believed that I wasted Ms. Washington’s time by going to tutoring and the meetings. Decisively, I stopped seeking help and was disengaged. This feeling of not belonging resulted in my attempt to take my own life, which was the only thing that I felt would stop everything.

Just as the Los Angeles Times article suggests, “all teachers, in special or general education, should be able to recognize unusual behaviors in children that could help identify disabilities...[but go undiagnosed because there]...is lack of understanding...[and]...are sometimes labeled bad by other children and even adults” (Buffa, 2012). This study highlights
the implications of my own experiences with being diagnosed with TS and a learning disability. It illustrates how the actions of teachers and peers could further lead to negative influences on a child’s academic performance. This could result in him/her being bullied and labeled as a “bad” student who just needed to focus and study. I was able to finally get the help and the support I needed by turning to advocacy groups in my state. By having an advocate that was knowledgeable of the laws, I gradually started gaining the confidence I needed to speak up. I did not want to own my own TS identity. Things started to get better in school once I accepted myself with the encouragement of my mother and advocate.

Discussion & Implications: Unpacking abnormality by connecting CCT with TS

This study used CCT to examine my experiences of being diagnosed with TS and negotiating my identity within my public school, as well as how my experiences influenced my preferred communication outcomes when interacting with authority figures and peers. Co-cultural theory provides an insightful framework that clearly highlights the variety of communication practices I enacted to negotiate barriers, assimilation, and separation. The use of CCT has extended the applicability and understanding of autoethnography while making an important contribution to the knowledge of co-cultural group studies. Although this study corroborates Wadman, Tischler, and Jackson (2013) research on the negative effect of TS on social interactions (including peers and new encounters) among adolescents living with TS, it also goes against their findings as bullying was prevalent in this study. Moreover, this study reaffirms bullying by peers as peer victimization was a problem (Bawden, 1998; Boudjouk et al., 2000; Cutler et al., 2009; Debes et al. 2010; Friedrich, Morgan, Devine, 1996; Stokes et al., 1991; Storch et al., 2007; Zinner et al., 2011). It also sheds new light on bullying by educators. I purposely went to great lengths to hide, ignore, or avoid my disability of TS, which is consistent with other studies (Cohen & Avanzino, 2010) in order to be accepted and not to be bullied.

This study also reaffirms how different power dynamics with CCT can work together to further marginalize co-cultural group members, which contributed to me not having much success with implementing strategies (Glenn & Johnson, 2012). The results of my study highlight how I used assimilation approaches (censoring self, developing positive face, dissociating, mirroring, and ridiculing self), in addition to other approaches, when negotiating roles with my teacher and peers to further my membership and acceptance within my school.

The communication orientation chart of preferred outcomes of co-cultural theory suggests that specific communication strategies will achieve the desired result for the co-cultural group member. CCT explains that the communication strategies enacted by co-cultural group members are influenced by the field of experience and abilities (Orbe, 1998a). However, the theory does not specifically address how co-cultural members negotiate a strategy when co-cultural group members are thrown into a co-cultural group without prior experience. For example, prior to being diagnosed with TS, I was considered a part of the dominant group within my school. However, after being diagnosed with TS, I was thrown into a co-cultural group without any frame of reference and was marginalized. I had no knowledge of how to effectively negotiate the proper preferred outcomes.

At the core of CCT is the notion that co-cultural group members respond to acts of discrimination and marginalization in both similar and different ways (Orbe, 1998a). Research needs to acknowledge that all forms of oppression are not manifested, perpetuated, or created equally. For instance, it is impossible to equate my TS disability with sexism, race, or homosexuality because the nonverbal and verbal tics resulting from TS directly impact my communication. I could not assimilate effectively because of the type of tics that were a part of my communication. My TS did not allow me to utilize the strategies effectively. This study
hopes to showcase this so that researchers who continue to seek understanding in regards to
the complexities of the inextricable relationship of power, culture, and communication may
serve as a cautionary message. Autoethnography may bring attention to the complexities of
this since the researcher has experienced marginalization directly.

Writing this autoethnography required me to be very reflective. I had to relive the public
schooling experiences of my diagnoses with TS, which brought up raw emotions that I had not
experienced in a while. What I have learned, and wish to bring attention to, is how
autoethnography has allowed me and can allow others to be reflective and understand how
power dynamics contribute to the communicative behaviors of these feelings. This may allow
us to reflect, grow, and become a society that is held accountable for its past, present, and future
actions within the public school setting.

With current educational policies and reforms being debated and discussed that focus
on bullying, students with disabilities, closing the achievement gap, and school safety,
understanding how school leaders and educators in power contribute to and further marginalize
at-risk students such as those living with TS is critical and must be acknowledged. Hooks
(1994) explains that if educators are to provide the necessary conditions where learning can
most deeply and intimately begin when educating students that are in the margins, it is essential
that educators and school officials, “teach [and communicate] in a manner that respects and
cares for the souls of our students” (p. 13). Hooks acknowledged the essential truth that
teaching, caring, and transformation are closely connected, that educators must be
accompanied by a deep level of care in order for learning to take place within their schools and
classrooms.

By highlighting my experiences as a marginalized student with TS, it is clear that my
educators did not show a sense of care or respect when teaching and communicating with me.
Not being acknowledged and cared for by educators and peers negatively influenced my
academics, emotional and mental state, leading to feelings of isolation and hopelessness. No
other students at my school were diagnosed with TS; therefore, I was truly isolated and alone
from other co-cultural group members within the educational institution. This may have make
it harder for my school to acknowledge what I was experiencing and going through as a student
with TS since they had no frame of reference or interactions with other students who had TS
prior to my diagnosis.

Hyde (2004) argues that “acknowledgement is a communicative behavior that grants
attention to others and thereby makes room for them in our lives,” (p. 63) whereas negative
forms of acknowledgement like silence or disrespect expose people to a fate of social death (p.
64), therefore making positive acknowledgement a “moral thing to do” (p. 63). Fully
understanding the mechanism of power dynamics that may exist in public schools allows
educators to recognize the continued marginalization experienced by unheard and unnoticed
students. This may facilitate changes in addressing the communicative, educational, social, and
mental needs of such students. It is the moral thing to do.

In addition to theoretical advancements, there are applied implications for this work. I
recommend that community educational advocates be introduced in the school system for
parents and students when dealing with issues of bullying and academics related to special
education services. Although some schools may have parental liaisons, it is not required that
these liaisons automatically attend meetings with parents and their students. Moreover, because
these liaisons are employees of the public education system, they are part of and represent the
power systems and structures in place. Therefore, someone from outside of the school system,
such as a local nonprofit, should represent these parents and students as a community
educational advocate. McPartland and Nettles (1991) found that when community advocates
are introduced to at-risk students and their families within the school system, positive effects
are found in improved student attendance and report card grades. Imagine if an advocate was
introduced by the school system immediately the moment I was initially diagnosed. I think that the experiences that I went through would have been very different and much more positive. An advocate may also help break down the power dynamics and influence of the school officials so that the voices of the parents and the students are actually heard and listened to.

In response to the bullying that I experienced and others may experience in school, I believe that the adoption of anti-bullying programs for their students and the school officials is essential and crucial if the school wants to create a safe environment for all students. Some suggestions include creating a curriculum program connected to the academic standards where students and teachers discuss literature, role-play, and establish a definition of bullying in accordance with a common set of rules (see Holmgren et al., 2011). School officials should also implement a program that includes parents in order to minimize bullying behavior through behavioral interventions and instructions (see Drosopoulos, 2008). My study highlights the negative effects that bullying may have on the learning and emotional state of students who experience it day after day from their peers and from their teachers.

Co-cultural theory allows the power dynamics within the school system to be exposed, and gives voice to the communicative experiences that I encountered. CCT makes an assumption that co-cultural group members may be born into their co-cultural group. Although this may be the case for many co-cultural group members as shown by previous studies, my own experience highlights that co-cultural groups are not always clearly defined.

Before being diagnosed with TS, my field of experience within my public school did not result in any marginalization. However, once I was diagnosed my reality radically changed. I did not initially know how to process or be successful within the dominant structure of my school as I previously did. I was treated very differently by my teacher and my peers, which resulted in my grades dropping, being bullied, and not knowing how to effectively communicate within the dominant systems of my school. CCT may wish to expand the definition of a co-cultural group member, since I was not born into marginalization, but was thrown into being marginalized.

**Conclusion & Future Research: Where do we go from here?**

The purpose of reflecting on my experiences with TS in the public school setting is to help propel change and hope within our educational institutions and organizations because “negative evaluations happen far too often and can motivate a variety of undesirable acts” (Adams, 2011, p. 143). To further disrupt and encourage change within the power dynamics within public schools, reflection and more research needs to be completed. This autoethnography is not a one-size fits all profile of what students with TS experience, but it is a glimpse into how power dynamics within a school may influence the communicative practices of students with TS.

It is necessary to conduct more research in this area, particularly, researching the experiences of adults living with TS and how they negotiate their identity in social settings, higher education, work, and in relationships. Future research may also want to consider how the pedagogical practices and curriculum reinforce the marginalization of co-cultural members, especially students living with TS. This specific study utilizes autoethnography as a methodology, other studies may wish to use more diverse methods such as interviews or surveys and include more co-researchers. The management of public school systems and organizational structures should be explored. More studies may also wish to explore other co-cultural group members where their field of experience drastically changed from being accepted or apart of the dominant co-cultural group to being labeled and seen as an outsider. In closing, since most studies predicated upon CCT utilize other, more detached, qualitative methodologies to give voice to the communicative practices and experiences of co-cultural
group members, more studies should augment autoethnography to allow for the voices of the marginalized to be directly heard since the researcher can speak directly to their experiences.

If marginalized individuals are to overcome their traumatic school experiences resulting from the power dynamics, educational institutions and organizations will need to take responsibility, and implement policies and procedures that recognize and address how certain power dynamics continue to further isolate students already in the margins. Only by acknowledging that public schools contribute to the creation of trauma and the development of feeling of being abnormal by these marginalized students, conversations and changes within educational policy and school settings may then begin to happen. Olson (2004) argues, “If we continue to give voice to those who have been silenced...and to give silence and hearing to those who have been voiced, we can make a difference” (p. 30). Indeed, this paper manages to reinforce this suggestion by being able to expose the influences power dynamics within public schools have on the communicative behaviors and the schooling experiences of these unheard, neglected, and marginalized students, including myself.

References


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