What Does it Mean to be Autistic? Examining How Identity Threats and Coping Strategies Influence the ASD Identity through Analysis of Identity Talk in Online Communities.

Completed Research

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Abstract

This study employs a grounded theory approach to examine how autism spectrum disorder (ASD) individuals make sense of their identity through online communities. Findings indicate that the autism diagnosis and perceptions of the diagnosis create identity threats which ASD individuals cope with in constructing and managing their identity. The autism diagnosis establishes a prescribed identity (i.e., identity an individual or social group is told they have) while others’ perceptions of the diagnosis create a stereotype identity (i.e., identity an individual or social group is assumed to have). These threaten the identity motives of belongingness, distinctiveness, self-esteem, and self-control/regulation. In order to manage these threats, ASD individuals employ the coping strategies of acceptance, online social support, digital insulation, positive distinctiveness, disidentification, concealment, and fantasy. We explore the impacts of these threats and coping strategies on autism identity sensemaking and explicate the implications for practice and research.

Keywords

Online communities, autism spectrum disorder, identity talk, identity threats, coping responses

Introduction

Autism spectrum disorder (ASD) individuals face struggles in negotiating their identities, both in terms of how they see themselves and how they believe others perceive who they are. ASD falls into the category of an “invisible disability,” which includes conditions and characteristics that may not be physically discernible to others (Santuzzi et al. 2013, 2014). As a result, individuals with ASD perceive that their disability is not well understood—or even acknowledged—by those who are “neurotypical” (NT) (i.e., individuals without neurological conditions) (Brownlow 2010), and may even struggle to understand their ASD identity themselves. Self-definition and self-advocacy, observed in the neurodiversity movement of the 1990s (Brownlow 2010), have become essential in a world where NT individuals tend to proliferate stereotypes of ASD individuals as mentally disabled, aggressively antisocial individuals (Davidson 2008; Davidson and Henderson 2010). In some cases, professionals also have focused on the deficits of autism rather than viewing it as a difference in how the mind works (Brownlow 2010). This focus has resulted in an increase of self-advocacy and awareness by ASD individuals (Ortega 2009; Parsloe 2015), who seek to understand who they are rather than who they are expected or told to be.

ASD is a neurodevelopmental (i.e., present from birth) disorder which is characterized by social-emotional reciprocity issues associated with social interaction, difficulties in developing and maintaining relationships, sensory processing issues, and focused interests which may include rigid or repetitive patterns (American Psychiatric Association 2013). The Center for Disease Control refers to social-emotional reciprocity challenges as deficits in reciprocating in social interactions, which include both socializing itself (e.g., communicating, sharing interests, understanding social cues) and emotional interpretations and responses (CDC 2016) in varying degrees. According to the CDC, ASD is one of the fastest-growing
developmental disabilities with 1 in 68 children identified with ASD compared to 1 in 88 in 2008 (Christensen et al. 2016).

Further, because of these challenges, which often manifest in the physical social world, many ASD individuals gravitate to the online medium to explore and make sense of their worlds and where they fit in (Brownlow 2010; Davidson 2008). Face-to-face NT conversations can move too quickly for ASD individuals whereas online they have more control over the communication speed (Benford and Standen 2009; Davidson 2008). Online forums specifically offer a more structured communication environment which does not require synchronous communication and allows for additional processing time (Burke et al. 2010). Online communities provide a unique opportunity to study how ASD individuals engage in online communities to make sense of who they are and how these communities accommodate them.

The purpose of this study is to better understand how ASD individuals make sense of their identity through online communities. Using a grounded theory approach, we address this research objective by observing and analyzing data from two popular ASD online communities, AsperClick and AspiesCentral. Findings suggest that ASD individuals perceive threats to their perceptions of self as a result of the identity they are told they have (i.e., prescribed identity) and the identity they are assumed to have (i.e., stereotype identity). These impact ASD individual’s perceptions of belonging, their sense of distinctiveness, their self-esteem, and their sense of self-control and regulation. In attempting to cope with these threats ASD individuals engage in coping strategies which influence their ASD identity. According to the literature, threats to identity have an impact on identity perceptions (Breakwell 2015; MacLeod et al. 2013). While prior literature has examined how ASD individuals make sense of their identity (Brownlow 2010; Ortega 2009; Parsloe 2015), only Giles (2014) has examined the influence of a specific identity threat (i.e., changes to the DSM-V). We seek to fill this gap by distinguishing the specific identity threats created by the diagnosis and assumptions surrounding autism, and how ASD individuals cope with these threats to make sense of their identity. By understanding the identity threats facing ASD individuals and how they cope with these threats, we can better understand what it means to be autistic and in doing so we can better accommodate these individuals in the workforce and education. Given the Association for Information System’s (AIS) open letter to its members emphasizing its core values of diversity and inclusiveness (Thatcher 2017) and recent trends in the IS discipline, such as a special issue call on social inclusion by Information Systems Journal, the results of this study can foster a better understanding of ASD identity that could guide more inclusive practices within the IS discipline and broader STEM fields.

Background

Identity revolves around “who I am” as an individual, “who we are” as a group, as well as in relation to others and places or things (Boudreau et al. 2014; Carter and Grover 2015; Vignoles 2011). McCall (2003) conceptualize individual identity as having two poles from “who I am” to “who I am not,” they are concepts that can stretch (i.e., concept stretching from Chimezie and Osigweh (1989)) to group level identity as well. One could easily conclude that if individual identities include conceptions of what is part of the identity and what is not, then social identities would have these as well.

Identity threats endanger the value, meaning or enactment of an identity to which individuals initiate coping responses in order to manage or remove them (Breakwell 2015; Petriglieri 2011). According to Petriglieri (2011), threats to the value of an identity negatively influences self-esteem while threats to the assumptions and meanings of the identity threaten perceptions of distinctiveness (e.g., uniqueness). There are also threats which result from being unwillingly categorized into a group (Ellemers et al. 2002) as well as being viewed negatively for one’s group membership (Steele 1997). These threats to identity result in an inherent need to restore a state of equilibrium which initiates coping responses. Petriglieri (2011) discusses different responses to threats including discrediting of the source’s validity (i.e., derogation), hiding parts of the identity (i.e., concealment), presenting identity-enhancing information (i.e., positive distinctiveness), changing the importance of the identity, changing the meaning, and deleting the identity entirely. Positive distinctiveness is similar to reframing where an individual transforms the meaning to something more positive (Ashforth et al. 2011; Ellemers et al. 2002). Disidentification, on the other hand, involves defining who one is based on who one is not (Fiol et al. 2009) and this can lead to a more positive spin on the identity as well but the results can also be negative. Another way that individuals cope with identity threats is through social supports by discussing the threats with trusted others in order to make sense of the identity (Devine-Wright 2009). These social buffers provide a safeguard against identity threats (Ashforth et al. 2011; Ellemers et al. 2002).
Another way to safeguard against the impacts of identity threats is to fantasize about something better and avoid (e.g., escape) the problem altogether (Breakwell 2015).

Internet-based or online communication has been shown to be an assistive tool for individuals with social deficits (Brownlow 2010; Caplan 2010; Davidson 2008). Benford and Standen (2009) found that ASD individuals were more comfortable communicating over the Internet which they found to provide a sense of anonymity, a flexible communication speed, and a sense of control. As ASD individuals prefer asynchronous forms of communication (Benford and Standen 2009; Linton et al. 2014), such as online forums, these communities provide access to data that may not be as easily obtainable offline. It must be noted that a recent study examined the discourses of ASD individuals on AspiesCentral (AC) (Parsloe 2015). Parsloe collected posts written from July through October 2012 from “The Spectrum” section of the site and analyzed the posts using a netnography and discourse analysis approach supplemented with interviews. Although Parsloe’s work is similar to this study, her work lacks a theoretical framework to ground her findings and to build theory that explains how ASD individuals make sense of their ASD identities. The current study leverages and builds upon theories in the identity literature to explain this phenomenon. In doing so, we focus on the threats that the diagnosis and perceptions of the diagnosis create and how ASD individuals cope with these threats to construct and manage their ASD identity. Specifically, through a discursive analysis of forum postings on two ASD forums, we examine how ASD individuals cope with threats to their ASD identity, which can further our theoretical understanding of identity threats and coping strategies.

**Research Approach and Methods**

The context for this study consists of two online ASD community forums, AspiesCentral and AsperClick, the former of which has been around since 2010 and the latter since 2012. AspiesCentral has over 9,000 members who have posted around 330,426 times within 15,985 discussion threads. The number of members was not made available by AsperClick, but members here have posted around 169,998 times within 6,360 discussion threads, indicating a smaller but active community. Posts by individuals who indicated they did not have autism, such as family members of someone with autism, were not examined. Thus, the sample consists of individuals from a variety of genders, age groups, and locations who are diagnosed or self-diagnosed with autism.

For this study, we utilized a grounded theory research approach for the data collection, analysis, and interpretation. Grounded theory is an inductive, systematic approach to theory development (Charmaz 2014; Wolfswinkel et al. 2013). Researchers enter a study with certain guiding ideas to assist in navigating the context, and they are guided by the initial research question(s), with the goal of building theory. Data is analyzed and interpreted through an iterative coding process in which coding adapts and adjusts as new insights are gained. In this study, we seek to build theory around how ASD individuals engage in identity talk in online communities to make sense of their identity. Data for these studies can include digital fieldnotes or e-fieldnotes (Sanjek and Tratner 2016), textual data such as message board posts, visual data such as pictures, and even media such as videos. They can also be supplemented by interviews and surveys, but in this study we focused on interpreting the discourse (i.e., talk) around the ASD identity in online communities. Data collected is initially coded which leads to the development of categories and focused codes, and this can lead to more directed data collection and possibly re-examination of earlier data (Charmaz 2014).

**Analytical Approach**

For the purpose of this study, the primary researcher immersed herself within the ASD communities strictly as an observer and not a participant. Due to the diversity inherent in autistic individuals, digital ethnographic methods provide a good means for examining this context in-depth (Kozinets 2010; Lazar et al. 2010). This nuanced understanding of the context then informed our interpretations of the ASD identity processes experienced in the online communities. IRB stipulated that only publicly available (i.e., does not require a login) data be collected and this limited the methodology to passive observation rather than participant-observation, and thus there was no need to obtain informed consent. Given the large number of discussion threads, we used keyword searches on the forums to obtain a sample of threads to analyze. A total of 120 forum threads were analyzed across the two online communities. Data included multiple page forum threads and posts which were converted into PDF documents and observational e-fieldnotes. These
documents were uploaded into MAXQDA 12 for coding. Data initially was collected as it related generally to the research questions, but as themes emerged the codes became more focused. There were a total of 765 coded segments from 120 documents.

The final coding scheme is shown in Table 1. Focused codes are grouped into the relevant categories which emerged through the iterative process of data analysis and theorizing. Some coded segments fell under the “identity talk” category, specifically if they were centered on discussing identity. It was from this category and its subcategories that many of the identity threat and coping response categories emerged.

<table>
<thead>
<tr>
<th><strong>Identity Talk Categories</strong></th>
<th><strong>Criteria</strong></th>
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<tbody>
<tr>
<td>Cure</td>
<td>Discussions around curing autism.</td>
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<tr>
<td>DSM</td>
<td>Discussions about the diagnostic manual.</td>
</tr>
<tr>
<td>Labels</td>
<td>Discussion around autism labels (e.g., Aspie, Autie).</td>
</tr>
<tr>
<td>Relationships</td>
<td>Discussions around developing and managing relationships for ASD individuals.</td>
</tr>
<tr>
<td>Self-Diagnosis</td>
<td>Discussions around autism self-diagnosis and its relation to actual diagnosis (e.g., if self-diagnosis has negative impacts on diagnosis).</td>
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<tr>
<td>Technology Enabling</td>
<td>Discussions around how technology has enabled ASD identity sensemaking.</td>
</tr>
<tr>
<td>Who am I</td>
<td>Discussions around understanding autism and what it means for an individual’s sense of self.</td>
</tr>
<tr>
<td>Work</td>
<td>Discussions around obtaining and keeping employment for those with autism.</td>
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<th><strong>Threat Categories</strong></th>
<th><strong>Criteria</strong></th>
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<tr>
<td>Prescribed identity</td>
<td>Community members discuss the medical community and society's prescriptions for who they are as ASD individuals.</td>
</tr>
<tr>
<td>The System</td>
<td>Community members mention “the system” when discussing their ASD identity.</td>
</tr>
<tr>
<td>Society</td>
<td>Community members discuss who they are told to be by society.</td>
</tr>
<tr>
<td>Medical</td>
<td>Community members discuss who they are told to be by the medical community (e.g., their diagnosis).</td>
</tr>
<tr>
<td>Stereotype</td>
<td>Community members discuss assumptions about who they are as ASD individuals.</td>
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<tr>
<td>Belongingness</td>
<td>Discussions around fitting in or not and feeling like they fit in with the online community.</td>
</tr>
<tr>
<td>Control</td>
<td>Discussions about not being able to control words or actions, often related to the diagnostic criteria (e.g., emotions, social interactions).</td>
</tr>
<tr>
<td>Distinctiveness</td>
<td>Discussions around distinguishing ASD individuals from NTs, fear of a loss of distinctiveness with the changes in the DSM, and a fear of not being autistic.</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>Discussions about negative perceptions of self and one's ability to do certain activities or tasks (e.g., job skills, social interaction).</td>
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<th><strong>Response Categories</strong></th>
<th><strong>Criteria</strong></th>
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<tr>
<td>Acceptance</td>
<td>Discussing accepting parts of the prescribed or stereotype identity, either in a positive or negative way.</td>
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Findings

Analyses resulted in the identification of two main threats to the ASD identity: stereotypes and prescribed identity. Stereotypes are the assumptions around who ASD individuals are assumed to be by others. Prescribed identity, which we define as the identity an individual or social group is told they have, creates a perception that autistic individuals should or should not act a certain way. For this context, the prescribed identity results from the medical diagnosis; inherent in this is how ASD individuals perceive that the medical community has dictated what constitutes characteristics of ASD individuals. Stereotypes come from assumptions held by those outside the group as perceived by those in the group. In this study, prescribed identity threats and stereotype threats are those threats that are perceived by the threatened group. Stereotypes and prescribed identity threaten an individual's and social group's motives of distinctiveness, belongingness, self-esteem, and self-control. The coping strategies that ASD individuals employ to respond to these identity threats include acceptance, online social support, digital insulation, positive distinctiveness, disidentification, concealment, and fantasy. Representative (not exhaustive) quotes for the findings can be found in Table 2.

<table>
<thead>
<tr>
<th>Identity Concepts</th>
<th>Representative Quotes</th>
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<tr>
<td>Identity Threats</td>
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<tr>
<td><strong>Prescribed identity:</strong> The identity an individual or social group is told they have.</td>
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<tr>
<td>A. Autism can be cured</td>
<td>&quot;'Cured' is a very short-sighted conclusion, and I absolutely understand how frustrating that would be. There's no 'cure', because you're not sick, we're just different.&quot;</td>
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| B. ASD individuals are disabled | "I don't think of myself as disabled at all. There are distinct advantages to my mental structure, and this is becoming truer all the time in our modern world."
"... ASD is not a disability, but a different variant of neurological development. We deviate from the norm, but we're not diseased. Hence the designation 'neurotypical' for people that are 'the norm'."
| **Stereotype:** The identity an individual or social group is assumed to have. It is the fear of being seen in a negative light due to one's group membership (Steele 1997) | |
| A. ASD individuals are abnormal | "you don't look autistic' is quite a common one, which really annoys me. Another is 'But you seem normal'"
"I told my friend that I think I might have Asperger's, and I totally got the 'but you seem normal' and 'I don't think anything Is wrong with you'"
B. ASD individuals are all the same

“There's no set way to be aspie, all aspies are all different and we all have very different personalities. You shouldn't let a label - and in particular stereotypes - define who you should be and how you should be - it’s ok to be yourself”

C. ASD individuals are violent

“Well, I suppose stopping the press sticking an AS label on every rouge shooter who pops up around the world would do wonders…education on what Aspergers is, or what an ASD is would be good.”

“They assumed because I had the Asperger's diagnosis I must also have anxiety, violent outbursts etc. To go with it (I definitely did not) and needed to be tranquilized on medications.”

**Threatened Identity Motives**

**Belongingness:** A fundamental need to be included and accepted. (Vignoles 2011)

“Throughout my life, I’ve been silent about my diagnosis because I got the feeling that it was this terrible secret that no one could know about or they would judge me.”

“... I was the only one who had worried about this. I sometimes fear that I lean more towards having Schizophrenia than Autism because I have found solitude and acceptance with Aspie/Autie communities.”

**Distinctiveness:** A need to stand out and be unique. (Vignoles 2011)

“Autism does define me but not in a negative way, it is just because it is all that I am. I wouldn't be me if I didn't have autism.”

“...the word "Aspie" doesn't mean anything to most people. Maybe we need to come up with another name to re-brand ourselves with.”

**Self-Esteem:** A need to view the self in a positive way. (Vignoles 2011)

“Pretty low self-esteem. Mostly because I make a fool out of myself if I get confident, seeing as I'm very good at saying the wrong thing or falling flat on my face because I’m not concentrating on walking.”

“I tend to lack self-confidence and I often don’t believe when someone tells me I’ve done a good job or that something has been done well.”

**Self-Control:** A need to be able to exercise control over one’s self (i.e., how one thinks, feels, and behaves). (Muraven and Baumeister 2000)

“After more than fifty years you might think that I would have at least some understanding of how my emotions work. But they still frequently leave me baffled.”

“I don’t always know the right words to say in particular situations and often I have to rehearse even basic communication. Panic sets in when I think I made a humiliating mistake.”

**Coping Response Strategies**

**Acceptance:** Accepting parts of the prescribed and/or stereotype identity. (Breakwell 2015)

“I have been accepting my autistic traits instead of fighting them.”

“But I’m learning to just accept my weirdness and eccentricities...and be myself...”

**Online Social Support:** Seek similar others in online communities for advice and support. (Devine-Wright 2009)
"Throughout my whole life I've never ever felt like I belonged - but once I started getting involved with others on the spectrum, for the first time I felt like I wasn’t such an alien outcast."

"I've been struggling with this for awhile now and was wondering if anyone could share some advice on how to cope with feelings of isolation...I want to change this outlook but am struggling...Any advice?"

**Digital Insulation:** The online community insulates ASD individuals from a focus on different dissimilar others to a focus on similar others.

"AC is the only place on the planet in which I socialize. Knowing that there are other Aspies out there by the cartload who make sense, speak a similar language to my own & can carry on an intelligible conversation has been life altering."

"This is an online community which I genuinely believe is an exceptionally positive place for people with Aspergers/autism and indeed those who know people with Aspergers/autism. This is a place where I can truly be myself. I don’t have to act "normal" when I am on here."

**Positive Distinctiveness:** Putting a positive spin on the identity. (Ellemers et al. 2002; Petriglieri 2011)

"I have super hearing!"

"Aspergers brings with it focus and determination; it also brings supreme cognition and memory - at least for me."

**Disidentification:** Defining who one is based on who one is not. (Fiol et al. 2009)

"I am an 'autistic person', not a 'person with autism'. It isn't an add-on or an accessory; it's who I am."

**Concealment:** Hiding one's identity from others. (Petriglieri 2011)

"Putting on an act is one way that a lot of us manage to cope in a NT world."

"The standard method for many autistics is to hide one's identity and 'Wear the Mask', or in fact often many masks..."

**Fantasy:** Creation of fantasy worlds or use of video games and books to escape reality. (Breakwell 2015)

"Have you ever wished you could run away to a world where everything is right? A place where you are accepted..."

"I find that with games (and books) I tend to use it as a form of escapism, I feel this is a short term fix and long term possibly does more harm than good."

**Table 2: Concepts and Representative Quotes**

**Discussion**

So what does it mean to be autistic? Based on a digital ethnography employing a discursive analysis of two online ASD forums, we found that, for many ASD individuals, autism is not a disease to be cured, but a part of who they are. It involves accepting diagnostic traits and learning to manage them in order to feel in control of one’s actions and to have a positive sense of self. ASD individuals are distinct from NTs and should not be generalized. They can be attractive, be able to socialize and act seemingly “normal” while still being autistic. ASD individuals learn to mimic NTs and conceal their true selves in the offline environment. In doing so they may come off as not being autistic when they really are. They are prescribed to be a certain way based on their diagnosis and this threatens their sense of distinctiveness. They seek support online to
understand what is and is not part of who they are, and this online environment digitally insulates them from a focus on their differences in an NT-dominated society to instead focusing on their similarities in a “world of Aspies.” Much of the draw of the online community is connecting with similar others in order to better understand who they are but also to feel a sense of belonging, a core identity motive. They try to find the positive sides of who they are and even put a positive spin on aspects of their identity that could be considered negative. They find no need to conceal who they are online and can instead create and project a self that reflects who they really are.

There are also strong impacts on self-esteem. Some ASD individuals often lack confidence due to a sense that they cannot always control their actions or words, or they can be overconfident in their sense that they are unique and gifted as a result of their diagnosis. Past challenges with social interactions, employment, and classes in which they were unable to control emotions, could not focus, or had trouble interacting with others can create a negative sense of self. If they see themselves for their inabilities they may try to cope with this threat through fantasizing about a better world or immersing themselves in fantasy worlds in video games and books. ASD individuals primarily sought to improve their self-esteem through seeking support online. They sought to find others who shared their struggles so as to feel like they belong but also to learn how to manage them. This ability to self-regulate when expressed by members of the community often was associated with a more positive self-image.

Conclusion

A more contextual understanding of what it means to be autistic can improve our understanding of how to accommodate ASD individuals in employment, education, and in society. The struggles they face in being told who they should be and who they are expected to be can result in concealing who they really are to others. By engaging with others like themselves online, they learn to manage their diagnosis and their perceived identity rather than trying to cure something that might never go away. Major IT companies, such as SAP and Microsoft, have adjusted their interviewing techniques in order to better accommodate ASD applicants (Nickelsburg 2016). Our findings can guide employers on how to better accommodate their ASD employees to obtain the benefits of a mind who views problems differently and can add new insights. Classroom environments that focus more on strategies that ASD individuals might find difficult, such as group projects or speaking up in class, can benefit from offering other methods for ASD individuals to add to the discussion. It is important to understand what it means to be autistic to ASD individuals because this will better inform us on how to accommodate them, communicate with them, and nurture their strengths using inclusive practices.

REFERENCES

Identity Threats and the ASD Identity


