



“I’m a normal autistic person, not an abnormal neurotypical”: Autism Spectrum Disorder diagnosis as biographical illumination

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ARTICLE INFO

Keywords:

United States
Biographical disruption
Experience of illness
Autism spectrum disorder
Diagnosis
Identity
Self-concept

ABSTRACT

Building on Michael Bury’s “biographical disruption” and Kathy Charmaz’s “loss of self,” which describe the deteriorative impacts of chronic illness on perceptions of selfhood, I propose “biographical illumination”—a transformed conceptualization of self and identity that is facilitated by but extends beyond medical meaning, *enriching* personal biography and social relationships. The concept is perhaps most applicable to experiences with neurological and neurodevelopmental conditions in which brain difference and personhood are perceived to be closely intertwined. In this study, biographical illumination is used to describe the experiences of autistic adults who learned of their Autism Spectrum Disorder (ASD) diagnosis during teen years or adulthood. Through an ASD lens, participants found explanation for their atypicality and developed a more valued self-concept. Learning of the condition did not disrupt their biography; rather, it became integral to and constitutive of it. With a new self-concept, participants re-gauged personal expectations for normalization and accessed communities of alike others, forging relationships that affirmed identity.

1. Introduction

Michael Bury introduced “biographical disruption” in 1982 to describe the disruptive impacts of chronic illness on concept of self, social relationships, and resources. Relatedly, in her seminal work concerning experiences of illness, Kathy Charmaz (1983, 1991) addresses the negative impacts of chronic illness on self and identity, the “loss of self.” Since then, researchers have developed this area of study by exploring the diversity of illness experiences and their impact on self. In many cases, the self is compromised by or reconciled with a medical condition (e.g., Bell et al., 2016; Llewellyn et al., 2014). In contrast, I introduce “biographical illumination” to describe a transformed conception of self that is facilitated by but extends beyond medical meaning and context, *enriching* personal biography and social relationships. The self is not negotiated; rather, through a medical framework, it is cultivated and refined.

Within medical sociology, research on biographical self often focuses on experience with *illness*—interaction with the social meanings and consequences associated with a disease (Conrad and Barker, 2010). However, the emphasis on illness excludes certain types of medicalized conditions, issues defined and treated as medical problems (Conrad, 2007). Biographical illumination is perhaps most applicable to experiences with neurological and neurodevelopmental conditions, inclusive of disabilities, such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorders (ADHD). Conditions associated with the

brain, in particular, are closely tied to understandings of identity and citizenship, which are negotiated in relation to and outside of medical jurisdiction (Illes and Racine, 2005; Brownlow and O’Dell, 2013; Conrad and Potter, 2000). For example, when the diagnostic criteria for ADHD expanded to include adult populations, it offered a new lens through which identity and lifelong challenges could be reinterpreted (Conrad and Barker, 2010).

In this study, biographical illumination is used to describe the experiences of autistic adults who acquired their diagnosis during teen years or adulthood. ASD is a disability (Centers for Disease Control and Prevention, 2016) that is medically defined as a “group of complex neurodevelopment disorders” (National Institutes of Health, 2015) characterized by social communication deficits and restricted/repetitive behaviors (American Psychiatric Association, 2013). Some studies on ASD diagnosis during adulthood find the experience to have positive impacts on self-identity, as the label provides insights into challenges (e.g., Ryan, 2013; Powell and Acker, 2015; Lewis, 2016). Analyzing narratives on ASD diagnosis, I demonstrate how autistic self is structured by but transcends medical articulation to shape understandings of identity, personal expectations, and community membership.

2. Biographical selves and diagnosis

Bury (1982) draws attention to three aspects of biographical

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<https://doi.org/10.1016/j.socscimed.2017.12.008>

Received 10 June 2017; Received in revised form 7 December 2017; Accepted 8 December 2017

Available online 09 December 2017

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disruption—disruptions of taken-for-granted assumptions and behaviors, self-concept, and social and material resources. Chronic illness is depicted as a transformative experience that progressively upheaves normal life. Researchers have applied and developed this concept to examine a range of health events, such as cancer (Alexias et al., 2015), stroke (Pound et al., 1998), multiple sclerosis (Green et al., 2007), and even tooth loss (Rousseau et al., 2014). Biographical disruption serves as a foundational concept for the development of other biographical models. Expanding this scholarship, biographical illumination depicts an experience that largely contrasts with biographical disruption.

In biographical disruption, selfhood faces re-evaluation as previous perceptions of self, expectations, pursuits, and relationships no longer comport with the new realities and limitations of being ill. Similarly, Charmaz discusses a “loss of self,” which she defines as “being involuntarily dispossessed of former attributes and sentiments that comprise one’s self-concept, as well as the actions and experiences upon which they are based. (...) The attrition of former attributes and sentiments results in changed feelings about self” (Charmaz, 1991: 257). The immediate demands of chronic illness diminish social relationships and limit usual activities important to individuals’ construction and reinforcement of self-concept. Consequently, individuals experience a loss of self, as elements imperative to its preservation are compromised (Charmaz, 1983).

Critics of biographical disruption contend that the model is not universal to experiences of chronic illness, as such pattern is specific to sudden onset during mid-life. Their critiques emphasize how disruption is mediated by contextual factors, such as age, illness histories, timing, and expectations. Concepts of “biographical flow” (Faircloth et al., 2004) and “biographical continuity” (Williams, 2000) describe instances in which illness is not notably disruptive because it is anticipated or perpetuates an existing narrative (Sinding and Wiernikowski, 2008; Lewellyn et al., 2014). For instance, when individuals have prior histories with or expect illness, disruption may be limited to the physical and not biographical (Williams, 2000; Faircloth et al., 2004; Harris, 2009). Researchers also find that previous hardships, not necessarily health related, may minimize experiences of biographical disruption from chronic illness (Hubbard et al., 2010). In Pandora Pound et al.’s (1998) study on stroke patients from a region of London with high unemployment and below average income, they find that stroke was accepted with resignation and pragmatism because it was consistent with the many other struggles that have come to define participants’ lives. Relatedly, Carricaburu and Pierret (1995) compares the cases of HIV positive hemophiliac and homosexual men to develop the concept of “biographical reinforcement,” which describes illness onset as reinforcing of extant identity and collective history.

Outside the context of chronic illness, scholars have also explored the emergence of other biographical selves in relation to terminal conditions (Locock et al., 2009), the liminality of in-between health states (Trusson et al., 2016), and contested illness (Madden and Sim, 2016). For cases of neurological and neurodevelopmental conditions, existing biographical frameworks present a valuable entrée but do not sufficiently characterize the experiences and impacts on self-concept. When the brain is centralized in conceptions of personhood (Vidal, 2009; Ortega, 2013), the medicalization of neurological conditions concurrently influences self and identity. This intimate relationship between brain and self is politicized in the neurodiversity movement, which constructs brain-based conditions like Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorders (ADHD), bipolar disorder, developmental dyspraxia, dyslexia, epilepsy, and Tourette’s syndrome as human variances and differences in brain “wiring,” as opposed to disorder or sickness (Jaarsma and Welin, 2011). Echoing the social model of disability, this perspective attributes the challenges of disability to oppressive social structures and ableism, which exclude and devalue brain differences (Drake, 1999; Wendell, 1989; Billawala and Wolbring, 2014). Although cases of brain-based conditions are managed lifelong, their experiences are not comparable to those of

chronic illness; and thus, alternative models for understanding biographical selves are needed.

The case of ASD provides an opportunity to examine how individuals mobilize their diagnosis to reconstruct biography. The diagnostic event is often overlooked or absorbed into narratives on being ill, but it is a crucial moment that calls for greater attention (Jutel, 2011). Research on contested illnesses—conditions not fully recognized by medical authority—in particular, highlights the importance of diagnosis to gaining legitimacy, health care, and the status of sick role (Glenton, 2003). This study focuses on how acquisition of diagnosis shapes conceptualization of self beyond medical definitions. Extant research illustrates the diversity of orientations between identity and a diagnosis (Mogensen and Mason, 2015). Relationships between self/identity and diagnostic labels (or lack thereof) are negotiated and managed (Goffman, 1986). For instance, individuals may endeavor to preserve self by separating the diagnosis (Fabrega and Manning, 1972; Madden and Sim, 2016) or accept diagnosis as part of identity (Giles, 2014; Conrad and Potter, 2000). By analyzing autistic narratives, this study explores how individuals engage with a diagnostic label to realize and develop their autistic selfhood.

3. Case background

This study analyzes the narratives of individuals who learned about their ASD diagnosis during teen years and adulthood. In this paper, use of the term, ASD refers to the current *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, fifth edition and the separate subtypes from the DSM-IV, which were dissolved into a single ASD classification in the DSM-5: autistic disorder, Asperger’s Syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. I refer to participants as “autistic,” instead of the person-first language “person with autism,” as this is the preference of participants.

ASD is a lifelong condition, yet it is most often associated with children (Stevenson et al., 2011). Research on ASD identification and intervention tends to focus on pediatric populations (e.g., National Research Council, 2001; Zwaigenbaum et al., 2015). For instance, on PubMed and Science Citation Index there are almost three times as many research publications concerning ‘autism and children’ than ‘autism and adults.’ Disability studies scholars contend that infantilizing ASD—portraying ASD as a childhood disorder—is detrimental to current and future autistic adults, as it ignores needs and challenges relating to employment, housing, and support services (Stevenson et al., 2011). Furthermore, with the exception of a few studies (e.g., Giles, 2014; Singh, 2011; Bagatell, 2007), research on experiences with ASD often focuses on caregivers’ perspectives. This is an issue not unique to ASD, but applies to other conditions in which diagnosed individuals are unable to provide their perspective or are discredited. Autistic perspectives are critical to research concerning ASD and its lived experiences. This study examines autistic narratives.

Participants diagnosed as adults come from the “lost generation,” the population of individuals who did not present obvious developmental impairments as children and were excluded from a classic autism diagnosis, but do qualify after the DSM-IV diagnostic expansion (Lai and Baron-Cohen, 2015). As such, this population is similar to adults diagnosed with ADHD after the DSM-III expanded criteria (Conrad and Potter, 2000). The process of diagnosing autistic adults is challenged by the availability of accurate accounts of developmental history (from adult’s childhood caregivers), developmental changes over time, and co-occurring psychiatric disorders (Lai and Baron-Cohen, 2015). Of the twenty-five participants who were diagnosed during adulthood, fifteen specified that they acquired an Asperger’s Syndrome diagnosis, which was introduced in the DSM-IV, and two specified high-functioning autism, which is frequently conflated with Asperger’s Syndrome (Baron-Cohen et al., 2001). Regarded as a mild form of ASD, Asperger’s Syndrome is differentiated from autistic disorder by typical language and cognitive development (American

Psychiatric Association, 1994). In most cases, participants pursued diagnostic evaluation to either confirm a self-diagnosis or identify the root of personal challenges. Reasons precipitating the pursuit of diagnosis varied; in addition to becoming aware of ASD through books and magazines, participants pointed to critical events, such as academic or job-related failure, nervous breakdown, and suicidal ideation.

Participants were sampled from autistic activism organizations. Autistic activism aligns with the broader neurodiversity movement in framing ASD as a human *difference*, not *disorder*. Activists' political agenda generally seeks to reduce the medicalization of ASD bodies and promote the social acceptance and valuation of autistic identity. Thus, participants of this study are more likely to experience biographical illumination than other autistic adults. Nevertheless, the case is especially valuable to illustrating how the self is realized through a medical lens.

4. Methods

This study is part of a larger comparative project examining ASD health social movement advocates, which employs ethnographic observations of movement organizations, interviews with advocates, and textual analysis. The research presented in this paper draws from interview data with self-identified autistic adults collected between 2014 and 2016. This study received ethical approval from the Institutional Review Board of Brandeis University.

4.1. Data collection

Interviewed participants were recruited during observations, through an organization's email list, and by snowball referrals. Autistic activism is comprised of a limited number of nationally established organizations. For observations, I first selected two of the most recognized groups, determined by media presence and related literature. After entering the field and gaining better understanding of organizations' structure and affiliates, two additional organizations were included for a more complete sample of active autistic activism groups (Charmaz, 2014). Observations were conducted at local chapter meetings/events and national multi-day retreats. During observations, I introduced the study and interview opportunity. I used one organization's email list of members to reach prospective participants who do not attend meetings in-person. Interview participants were encouraged to ask other self-identified autistic activists to contact me if interested in taking part in the project. Across all three recruitment strategies, I described the project as a study that seeks to understand autistic experiences with and perspectives on self-advocacy. Individuals interested in interview participation contacted me directly to learn more about the study and/or schedule the interview.

To accommodate diverse communication needs during interview, participants were asked to select their preferred mode of communication. Three chose to complete the interview by instant messaging and two by email. Limited by geography, five interviews were conducted over telephone. Twenty-seven interviews were conducted in-person at the participants' preferred location, often public spaces. Participants were provided information about the study and a consent form for review. Consent forms included information on confidentiality, risks and benefits, voluntary participation, and the contact information of the Institutional Review Board that approved this study. Prospective participants were allowed time to ask questions about the study and its procedures.

Semi-structured interviews were conducted to capture the perspectives of participants (Weiss, 1994). The questions were organized into four thematic categories: ASD diagnosis and early experiences, perspectives on ASD (i.e., definitions, descriptions, and theory of causation), ASD-related advantages and challenges, and advocacy and outreach involvement. Questions were opened ended (e.g., "What initiated the pursuit of a diagnosis?"; "Describe to me your earliest

Table 1
Characteristics of autistic participants.

| Demographic Variables | (n = 37) % |
|-------------------------------|---------------|
| Age of Official ASD Diagnosis | |
| Under 18 years of age | 29.7 |
| Over 18 years of age | 67.5 |
| N/A | 2.7 |
| Gender | |
| Female | 43.2 |
| Male | 37.8 |
| Other | 18.9 |
| Race | |
| Black | 10.8 |
| Asian | 8.1 |
| White | 81.0 |
| Highest Level of Education | |
| High School | 5.4 |
| Some College | 13.5 |
| Bachelor's Degree | 43.2 |
| Master's Degree | 27.0 |
| Doctorate/Professional Degree | 10.8 |
| Employment | |
| Employed | 64.8 |
| Student | 8.1 |
| Retired | 2.7 |
| Unemployed | 24.3 |

memory of hearing the term 'autism' or 'autistic.'") Probing questions were used to encourage elaboration and clarification of responses. Interviews were 45 min to two hours in duration. Interview audios were transcribed verbatim. Pseudonyms are used to preserve the confidentiality of participants.

4.2. Sample

Thirty-seven self-identifying autistic adults were interviewed. At the time of interview, participants were between the ages of 22 and 65. Demographic characteristics and distribution of autistic participants are presented in Table 1. Most participants (67.5%) were officially diagnosed at age eighteen or older, under the fourth or earlier editions of the DSM; of this group, two were originally diagnosed with ASD during childhood, but had the information withheld by parents until they were re-diagnosed in adulthood. Among those diagnosed under the age of eighteen, one participant was diagnosed as a toddler but did not learn of his diagnosis until his teen years. One participant identified as autistic, but did not possess an official diagnosis. Among those with an official diagnosis, seventeen specified having an Asperger's Syndrome diagnosis, two high functioning autism, one infantile autism, one "atypical development with strong autistic tendencies," and fifteen autism without specification of subtype.

18.9% of participants identified as gender non-binary, indicating "other" or writing in their own responses, like "between female and other." Singular they/them/their pronouns are used when gender-binary pronouns are not applicable. Representative of the participant population from ethnographic observations, the majority of interviewed participants (81%) are white. Participants have higher rates of education attainment and employment than the general autistic adult population. Population-based studies on autistic adults are limited, but one review finds 5–40% of autistic adults complete college and 24% of those who completed mainstream education are employed (Levy and Perry, 2011). Comparatively, 81% of participants completed a college education and 64.8% were employed at least part-time.

4.3. Data analysis

In my data analysis, I employed a grounded theory approach. Observation field notes, memos, and interview transcripts were coded

for analytic ideas and emerging themes (Charmaz, 2014). The qualitative coding program, Dedoose, was used to aid this process. Initial coding was first employed to identify themes, patterns, and special language. Through an iterative process, initial codes were then reorganized into key themes and concepts to refine a set of focused codes. Focused coding sorted data into major thematic categories and facilitated analysis. Axial codes were also developed to structure subcategories of focused codes, allowing elaboration within larger themes. Throughout data collection and the coding process, detailed notes and reflections were produced to record ideas, questions, and theory development. The concept of biographical illumination emerged from an analysis of excerpts coded for themes relating to diagnostic experiences.

4.4. Limitations

The participants of this study are perhaps more likely than other autistic individuals to experience biographical illumination because they were purposefully sampled from autistic activism organizations. Affiliation with these organizations suggests alignment with an ASD rights and acceptance agenda, or at the very least, no strong opposition against it. While success of autistic activism groups like Autistic Self Advocacy Network (ASAN) signify collective autistic interest in gaining cultural and institutional acceptance and representation, less is known about ASD-diagnosed individuals who object to these positions and want to be “cured” (Bagatell, 2010) and those who do not have opportunities to participate in ASD communities. Furthermore, autistic activism and neurodiversity-supporting organizations are typically dominated by “higher functioning” individuals (Ortega, 2009). The perspectives of autistic individuals with limited or no known communication abilities were not represented.

5. Analysis

I present the concept of “biographical illumination”—a transformed conceptualization of self and identity that is facilitated by but extends beyond medical meaning and context, *enriching* personal biography and social relationships. The distinctive feature of biographical illumination is the cultivation of self and knowledge about self. A medical framework, as examined here, can provide individuals a lens through which to see themselves with greater clarity. Exploring the case of autistic individuals who learned of their diagnosis as teens and adults, biographical illumination is depicted in narratives about (1) re-interpretation of self and identity, (2) adjustments to expectations of adaptation and intervention, and (3) ASD community entry and membership. Although participants diagnosed as children and adults shared similar attitudes and understandings of autistic selfhood, findings focus on the latter group to highlight the process and features of biographical illumination.

5.1. “Normal autistic”: understanding self through ASD diagnosis

Participants’ pathways to an ASD diagnosis during adulthood varied, as previously discussed in the case background. However the diagnosis was achieved, following its acquisition, many participants described a transformative shift in how they understand themselves and their identity. The diagnostic label carried medical and existential relevance. It provided participants an explanation for their atypicality, and concurrently, offered a framework with which to reinterpret and develop their self-concept. Behaviors and challenges of past and present were attributed new meaning and appreciation through the lens of ASD. Accordingly, the moral implications of these behaviors and challenges were re-evaluated.

Participants generally came to embrace the ASD diagnosis with a positive attitude. Understanding themselves as autistic revealed insights into who they are as individuals and accounted for experiences that previously eluded them. In the excerpts below, Hil and Lea illustrated

how gaining an ASD diagnosis drastically reframed the way they understood their atypicality—from devaluation to redemption. Prior to receiving the diagnosis, Hil identified multiple challenges and an inability to “keep up with others,” which they internalized as a personal failure of being “weird” and “broken.” Then, Hil experienced a revelation while reading Donna Williams’s autobiography on being autistic. Recognizing uncanny similarities between the author’s experiences and those of their own, they pursued an official diagnosis. By identifying as autistic and understanding their atypicality as “neurological,” Hil described a transformed concept of self from being an “abnormal neurotypical” to a “normal autistic person.” Hil realized there were others like themselves and normalized traits they previously perceived as undesirable and deviant:

It seemed like this whole huge collection of different things that were fucked about me. And all of a sudden, they were one thing. And all of a sudden, I recognized that there were other people who had the same constellation of differences. That there was a word I could attach to it. It was neurological. It wasn’t my fault. It wasn’t my parent’s fault. It just was. (...) The challenges are far less than they used to be when I didn’t know I was autistic. Because I no longer blame myself for the ways in which I seem not to keep up with others sometimes. (...) I blame myself for everything, yeah. I mean, I was just weird and different and broken, I felt in so many ways. And now ... Now, I’m a normal autistic person, not an abnormal neurotypical. [Hil]

For Hil, being autistic was not perceived as a medical *problem*. Instead, being autistic absolved them of fault because the diagnosis organized a comprehensive account of their fundamental difference and an alternative standard of typicality. Similarly, Lea had perceived themselves as being “just lazy,” “bad at things,” and “wrong” for reasons that were inexplicable. Following a nervous breakdown, Lea received an official ASD diagnosis, which their mother had recently suspected after reading about it in a book. Lea described the ASD diagnosis as being instrumental to their self-exculpation:

I didn’t get diagnosed until I was an adult, which was difficult because my entire life I thought I was just lazy and bad at things. And clumsy and just everybody just hated me for some reason. And I didn’t understand why and I thought that there was just this something dark and deeply wrong with me that I didn’t understand. And so, getting diagnosed was helpful because it made me understand why I do certain things. And what certain interactions or what’s happening in those interactions. And that was really useful. And it would have been nice to know that when I was a kid, but it’s not like—it’s not me being wrong. It’s me being different. [Lea]

One major source of suffering that participants described was the uncertainty of not knowing the reason for apparent differences. Participants mobilized the diagnosis to make sense of themselves beyond the framework of disorder and resolve ambiguities that previously strained their self-concept. As such, identifying as autistic is different from having an illness because participants take this diagnosis to articulate a general way of being. The condition does not disrupt their biography; rather, it is integral to and constitutive of it.

Participants contended that the ASD diagnostic label offered recognition, and thus the label itself is important to the validation of their self-concept. In the DSM-5, autism subtypes of the fourth edition were dissolved into ASD, no longer existing as independent diagnoses. Scholars have noted the potential impacts that these changes may have on autistic identity and community (Giles, 2014; Singh, 2011; Spillers et al., 2014). Participants were concerned about their qualification for ASD under the DSM-5 and perceived the reclassification as a threat to their identity. Speaking about this issue, Russel expressed worry about being excluded from the new classification. He equated the loss of his Asperger’s Syndrome diagnosis to the denial of his very existence:

Like they got rid of the Asperger's diagnosis. I am still upset about it. (...) Because it's like we don't exist anymore. And that I may no longer be classified under the current diagnosis standards. I'm probably blended in there somewhere. I'm probably still counted as having it. Um. But I'm not sure. And I don't have the money to go get retested. Because it was a very expensive test. (...) For me I think it's part of me now. It's a part of my, you know, it's a part of me. [Russel]

Furthermore, through an ASD lens, participants elucidated previous experiences to forge continuity between past and present selves. Unlike biographical reinforcement in which illness confirms previous constructions of identity (Carricaburu and Pierret, 1995) or biographical flow in which illness perpetuates existing narratives (Faircloth et al., 2004), biographical illumination generates new knowledge about self that is applied across time. A cohesive autistic selfhood emerges as the past is translated through the ASD framework. Reflecting on a childhood memory, Codey noted how an ASD framework offered explanation for why he had a “meltdown” at the baseball stadium. Similarly, Cynthia recounted how her challenges at work were, in retrospect, “obvious symptoms” of Asperger's Syndrome:

I mean looking back like I guess that certain like childhood experiences I had like it make a lot more sense in the context of, well, I'm autistic. (...) I remember one memory that sticks out to me. My dad took me to a baseball game. And it was way too loud and I just could not deal with it. I was six or something and just had a meltdown in this baseball stadium. And there was a restaurant in the baseball stadium, so he took me there and then we watched it on TV. And like, that's fine. It was [a] quiet restaurant. But how that didn't occur to my dad, that the noise was too much for an autistic kid. And that's why you're going to need to not take me to this baseball stadium. [Codey]

'Cause I was always getting frustrated at work at the IRS and hanging up on people, yelling at people, sometimes yelling at coworkers and managers sometimes 'cause I was just so stressed out. See, there was a lot of obvious symptoms of Asperger's right there, but no one knew. No one knew. [Cynthia]

Autistic self is depicted to transcend the timeline of diagnosis. Not only were personal challenges given new biographical meaning but strengths as well. Participants associated unique and desirable qualities to being autistic; for instance, having “autistic passion,” which is the ability to become deeply immersed in an interest. Reflecting on professional career and academic achievements, Ci-Ci attributed her successes to Asperger's Syndrome:

But, as I look back, I mean I think it sort have been dominant influence in my life. It's basically, I think my Asperger's traits have sort of is the reason I have been able to be successful in my job, that I did well at school, that I lived my life the way I did. [Ci-Ci]

Participants reinterpreted the past to align with present conceptions of self, conveying an uninterrupted biography in which autistic-self predicated acquisition of diagnosis.

Acquiring an ASD diagnosis and identifying as autistic facilitated biographical illumination. Participants described having a new lens through which to construct a valued self-concept and explicate the root of behaviors and challenges. Participants referred to the diagnosis to discover a temporally cohesive autistic self that has always *been* and only realized with a diagnosis.

5.2. Unfixable: adjusting personal expectations and developing new adaptation strategies

After gaining an ASD diagnosis, participants adjusted their personal expectations for normalization and reoriented goals and approaches. The incurability of ASD meant that becoming typical was not a feasible

endeavor; thus, participants shifted their strategies toward adaptation and accommodation.

After learning about their diagnosis, participants described comfort in understanding that their atypicality was not something that could be cured. Consistent with existing studies on ASD-diagnosed adults (Joshi et al., 2013; Hofvander et al., 2009), the majority of participants reported co-occurring diagnoses that preceded their ASD diagnosis; commonly mentioned were depression, obsessive compulsive disorder, ADHD, and nonverbal learning disorder. For those who were previously issued other diagnoses and pursued treatment, receiving an ASD diagnosis relieved them of the pressures of getting cured, and concomitantly, the profound sense of failure when treatments did not meet expectations. Participants indicated that understanding themselves as autistic allowed them to accept the limits of normalization. Illustrated by Lea and Felix, efforts to “fix” and “cure” their earlier conditions resulted in feelings of defeat. Lea described the “power” of realizing there would never be a “magical medication combination” that was going to transform her to be “like everybody else”:

You can't fix autism, which I know sounds worse to some people, but to me it was so much easier. Like there wasn't some magical medication combination I was going to find that was going to make me like everybody else. (...) So, I had to—instead of trying to fix myself all the time and beating myself up about not being able to, I had to accept it and accept these parts of me that I had been told were bad. And that was really powerful for me. [Lea]

When he thought he had depression and nothing else, Felix recalled feeling frustrated with waiting for the medications to take effect, so he could be “happy and well-adjusted and like everyone else.” He attributed his suicide attempts to the felt disparity between his expectations of treatment efficacy and actual response. Noting how he “kept falling short,” Felix implied an internalization of personal failure. After being diagnosed with ASD, Felix took solace in knowing that he would never be typical:

[Interviewer: *And what did the diagnosis tell you about yourself?*] That it wasn't the type of thing that I was going to cure. It was something that I had to adjust to. It was just a—I would just have to live in a different way instead of waiting for the drugs to kick in and the therapy to reach a breakthrough. (...) When I thought it was just depression, I thought eventually it would end. And it was the frustration of waiting for it to end and it not ending. That led to the suicide attempts as much as anything. (...) Sometimes I think getting a firm ‘no’ is easier than a ‘we'll wait and see’. (...) And when it was just depression there was the possibility that eventually I would be happy and well-adjusted and like everyone else. I had that to look forward to and I kept falling short. [Felix]

For participants, ASD provided a reason for why they could not successfully normalize, and as such, it encouraged acceptance and adjustment to these differences.

Participants found the diagnosis instrumental to recognizing the nuances of their difference beyond medical definitions, and in accordance, modifying personal expectations. Rick suggested that understanding oneself through the lens of ASD reorients attitudes because the very recognition that one engages in adaptation strategies in day-to-day life mitigates perceptions of and experiences with challenges:

It's a lot less difficult to work around something when you realized, ‘okay, I really—there really is such a thing as not being able to do eye contact well. And that's okay, just deal with it’. And then the dealing with it is the same ‘dealing with it’ as if you didn't know, except for it's not the same. Because you really know that you're adapting rather than trying to make it work in a forced manner. I think it's sort of like driving a car. Once you know that you have to shift gears, it makes it a lot easier to change speeds and such than just trying to wonder why the car is not accelerating or, you know,

going up to speed. [Rick]

As the ASD diagnosis rearticulated their challenges, participants pursued new management strategies, like requesting accommodations in school, using devices to help with sensory processing (e.g., earmuffs, sunglasses), engaging in self-stimulatory behaviors to lower anxiety (e.g., flapping hands, rocking body, shaking objects), and finding new jobs that are less socially demanding. Because there is no specific medication for ASD (though individuals can take pharmaceutical drugs to manage specific symptoms, like anxiety), strategies were primarily non-medical and adaptive. Described in the excerpts below, participants used the diagnosis to recognize their needs and access social and institutional resources:

And it took the diagnosis for me to actually realize what my impairments were and which meant that—it took that to recognize the ways I could actually cope. [Felicity]

(...) diagnosis totally a medical model word. That's what we're stuck with for now. You know, I do think that people need to be identified in order that we can meet others like us who can help us form the strategies that help us get through life. So that we can learn how to ask for accommodations. What accommodations might be helpful. [Hil]

In light of an ASD diagnosis, participants adjusted personal expectations and adopted adaptive strategies. While incurability is unfavorable in most medical contexts, participants—particularly those who had their challenges explained by other diagnoses in the past—preferred the permanence and inextricability of ASD. ASD offered relief from the pressures of normalization and the disappointments of failed treatment. Participants perceived ASD to be an intrinsic characteristic, which they had to work with instead of against.

5.3. “...like me with spots”: finding alike others in an autistic community

By identifying as autistic, individuals discovered and gained membership into autistic communities that offered more fulfilling social relationships and networks. Research on illness communities and support groups have highlighted how diagnoses promote community formation (Barker, 2008; Radin, 2006). As the diagnostic label organizes new understandings of self, it also implies commonalities with others who possess the same label. Thus, biographical illumination locates self within new social networks, giving rise to new social identity. Participants indicated that acquisition of an ASD diagnosis served as a passport into communities of individuals to whom they could relate; as one participant, Damian, remarked “I know my tribe.” Comparing their social lives prior to and after identifying as autistic, participants provided narratives that contrast a lonely and misunderstood past to a more socially enriched present. For instance, Winnie pursued an evaluation on recommendation from her life coach and Luba approached her doctor after failing an important exam and contemplating suicide. After learning that they are autistic, Winnie and Luba mobilized the diagnostic label to find alike others. Winnie described using her diagnosis as a guide to locate “other people like me with spots.” Upon discovering other autistic individuals, Luba expressed a sense of relief in realizing that she was not alone in her experiences:

Well, to me it feels liberating, sort of—comes to mind, but it's, I feel it's been wonderful that I'm like, I don't know, sort of, I was excited when I first got my diagnosis. I felt I just want to meet other people like me. It's like I've been an animal with spots. All my life I've been around other animals without spots and I feel I can start meeting other people like me with spots, you know? [Winnie]

And then, I was listening to a few other young women when they were talking about theirs and I thought that's me. I have that. I was just ‘whew. I'm not the only one.’ (...) And I just started listening to all their experiences and I thought, ‘this is me, yes. Finally, I'm not

alone’. And I just kept on going. I went to the social, pizza, and game night. And I met one of the members that I know from ASAN and I met some other people. And some of them are—one of them is my [best friend forever] right now. And I just—I got to know them and it was—I could talk if I wanted to and it was so free. And I finally found my life. [Luba]

Participants suggested that being part of an autistic community also facilitated and affirmed personal understanding of self. Codey was diagnosed with ASD as a toddler, but his parents withheld the information. At age fourteen, he learned of his diagnosis after researching his doctor and the medications he was prescribed as part of an alternative treatment program. In the years following this discovery, Codey reported feeling suicidal, which he attributed to early experiences and internalization of alienating messages about disability. However, after finding autistic communities with positive attitudes toward ASD, Codey felt a sense of belonging:

So, I went through a period between like ages 16 and 18 where I was very suicidal and just mentally ill, in general, and processing a lot of things that I realize now were like trauma from my upbringing and just from like my experiences. And I guess at a certain point, I was just like, ‘I'm not going to like get anywhere in my life feeling ashamed of everything all the time’. And like, ‘there has to be like some other perspective out there that isn't telling me that I'm like terrible because I'm disabled’. And luckily, just by the way that timeline worked out, that was when these sorts of organizations were starting to pick up speed. (...) So, like all those things sort of happening at the right time helped a lot in terms of feeling like I had a place in the world. [Codey]

Consistent with research that finds ASD-diagnosed individuals to have higher rates of suicidal ideations (Shtayermman, 2008), Codey reported feeling suicidal prior to finding ASD-positive communities and four other participants expressed having ideated or attempted suicide prior to receiving an ASD diagnosis. After acquiring an ASD diagnosis, participants used the label to locate autistic communities, which expanded their social networks and contributed to a more positive concept of self. In this way, communities facilitate biographical illumination.

While chronic illness can strain social networks and resources (Bury, 1982; Charmaz, 1983), acquisition of an ASD diagnosis enriched the social lives of participants. Mobilizing their diagnostic label, participants found autistic communities and a sense of belonging that they lacked before.

6. Conclusion

The key feature of biographical illumination is the enrichment and cultivation of self as structured by a medical framework. While this study applied the concept to describe the development of autistic selfhood, biographical illumination could also serve as a useful framework for exploring experiences with other neurological and neurodevelopmental conditions. For instance, biographical illumination may be applicable to research on ADHD, bipolar disorder, developmental dyspraxia, dyslexia, epilepsy, and Tourette's syndrome subpopulations who, similar to the autistic activists, support a neurodiversity model and perceive these conditions as human differences and not sickness (Fenton and Krahn, 2007).

For autistic participants, an ASD diagnosis signified a way of *being* that extended beyond its medical articulation to legitimize experience. Participants engaged with the ASD framework to construct more positive and valued understandings of self, which absolved them of previous self-perceptions of deviance and immorality. With new knowledge about autistic selfhood, participants re-gauged personal expectations and pursued other strategies to address challenges. Furthermore, the diagnostic label functioned as a passport into autistic communities

where participants discovered alike others who shared, and concomitantly validated, autistic selfhood (Barker, 2008).

Acquisition of a diagnostic label typically increases medical engagement, but when diagnosis evokes biographical illumination, it can paradoxically *reduce* medicalization, as individuals extract understandings of self from the label. Participants did not fully contest the medicalization of ASD, as some mobilize the diagnosis to gain needed accommodations and services; rather, they limited the defining power of medical authority by underscoring the condition's inextricability from self and related strengths.

Future research on biographical illumination should consider how the phenomenon influences healthcare decision-making and practice. If a condition is constitutive of self, how do patients and professionals discuss challenges and negotiate intervention? How is the transformed self situated and managed within a medical context? In addition, the concept proposes an experience with medicalized conditions that may complicate conventional relationships between patient and medical authority. When transformed selves exist both within and outside of medical boundaries, how might this shape perceptions and enactments of expertise?

Acknowledgements

I would like to express my deepest appreciation to James R. Jones, Olivia Nicol, Jaleh Jalili, Alexis Mann, and Thomas Bertorelli for their friendship and feedback, and Peter Conrad, Sara Shostak, and Laura Miller for their mentorship. I would also like to thank the National Science Foundation (#1636976), The Lurie Institute for Disability Policy, and Mellon Foundation for their support in funding this study.

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