

“Gender Differences in Autism”: TED Talks as Inclusive Spaces for Co-creation of Collective Memories

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Abstract

Autism Spectrum Disorder (ASD) has been historically studied, identified, and diagnosed more in males than females which can be attributed to a range of factors other than biological. The preponderance of males with autism is often associated with the Extreme Male Brain (EMB) theory which contends that this male bias is interceded by the amplification of male-biased sex differences in the expression of autism-associated traits found in typical populations. This long-held notion of attaching autism to the male gender had severely impacted the females on the spectrum leading to late diagnosis, misdiagnosis, and “masking” in order to blend in. Media also played a role in the near-exclusive portrayal of autistic people as white males which is outrageously unrepresentative of reality. The present paper analyses the narratives of self-identified autistic women about their experiences shared through TED Talks which offer both individual and collective counter-narratives to articulate new understandings. The paper attempts a qualitative interpretation of 5 such talks to demonstrate how speaking about these narratives in public and influential spaces like TED Talks de-constructs collective memories (process) and constitutes constructing *La Memoire Collective*¹ between the knowledge of experience and shared memories.

Keywords: autism, gender, collective memory, social identity, TED talks

1. Introduction

The formation and purpose of personal and collective memory is now a long-established field of academic study (Halbwachs, 1992). Collective memory is a form of memory that transcends individuals and is shared by a group usually based on a common identity. Collective memories are affected by cognitive and emotional factors developed within the framework of human interactions with other humans or cultural artifacts and are shaped and disseminated through narratives. In *Memory from A to Z*, Yadin Dudai observed that “The term ‘collective memory’ refers to three entities: a body of knowledge, an attribute, and a process” (2002, p. 5). The present article attempts to conceptualize and probe the construction of collective memory as a process, reshaping the existing notion of attaching autism to the male gender alone by examining the TEDx talks shared by autistic women.

As human interactions become more digital and have an impact on cultures around the world, digital platforms are becoming more and more significant in the production and transmission of knowledge. People obtain their knowledge and entertainment from social media platforms, online news sources, and videos, and this consumption profoundly shapes social identities and affects public opinion. Users of the web generate not only communication and social connection, but also memory, a feature that has previously gone unnoticed. This memory creation occurs on blogs, social networks, and generally any platform that enables the exchange of user-generated content, and the selection of content that users feel is significant. Memory is inextricably linked to this process in a way that the body and its memory can never be separated from the social web, which has developed into a place where identity and meaning are produced. In contrast to the conventional idea of the narrative being built by a teller for a reader, the digital medium functions as a trigger for narration based on memory, ultimately forming a collectively constructed story. The memories recorded and archived on the social web, which can potentially be accessed by the vast public of Internet users, can

¹ *La Memoire Collective* is the French equivalent phrase for collective memory.

therefore regard as both an autobiographical past and the founding collective past (Bartoletti, 2011).

In 1984, the non-profit organization known as "TED," which stands for Technology Education and Design, was founded. When the organization's curators started providing brief, free, unrestrained, and instructional video pieces in 2006, it shot to fame in popular culture. The format of TED Talks, which are frequently given in chic studios with fashionable backdrops, concentrates on the presenter and uses a few, very intentional visual aids. The maximum run time for a TED Talk is 18 minutes, and they are not as impromptu as they might seem. Presenters are well-trained and given instructions on how to adhere to a particular presentation formula that makes the most of storyboarding and emphasizes the subject's passion (Romanelli et al., 2014). TED lectures are now universally acknowledged as a platform with enormous potential to alter both the educational landscape and people's perceptions. TED Talks are particularly well-liked among millennials, which promotes the exchange of wise and original ideas. The platform does not, however, only appeal to younger generations. The growing number of views for TED Talks videos is proof that viewers from a variety of age groups started to accept it. On the other hand, TEDx events are independently run, by various groups, and with a free license from TED. To put it another way, the community that sponsors each TEDx event plans the presentation, but TED owns and develops the overall structure. This guarantees accurate, first-rate information and provides a tailored solution to the issues or achievements of that group. Inclusivity, which permits members of historically underrepresented groups to participate and speak, including women, the disabled, people with neurodivergent identities, transgender people, and others, is one of these events' most crucial qualities. According to Valkenberg et al. (2016), a significant body of research demonstrates that media consumption impacts public opinion, therefore representation in digital media like TED talks is crucial. Currently, there are hundreds of TEDx videos available on Youtube, which feature dynamic speakers educating and conversing on a wide range of topics including women empowerment, gender neutrality, inclusive education, mental health, social stigma, and more.

Autism Spectrum Disorder (ASD) is characterized by a heterogeneous group of neurodevelopmental disorders and is well documented with a predominance in males which is now being questioned. Literature over the years has documented a male-to-female ratio of approximately 4:1 (Rynkiewicz et al., 2016). Less is known about women with autism since most published research on ASDs focuses primarily, and in some cases solely, on males (Nowell et al., 2018). For quite a long time, it was presumed that women with autism shared the same neurobiology as men with autism and behaved similarly. This most likely would have resulted in a male stereotype of ASD, which would have led to many professionals retaining unconscious gender prejudices and being less attentive to autistic symptoms when they appear in females (Loomes et al., 2017). The number of undiagnosed female instances of autism has grown as a result of testing bias and the possibility that women may express their disability differently. There is strong evidence that the experience of being autistic differs between males and females (Lai M-C et al., 2015). Autism is influenced by social factors as well, which may help to explain why so many female autistics go undiagnosed. For instance, the criteria were created mostly based on research on boys and social expectations that women are more social than boys. Girls with autism who were not diagnosed as children struggle to understand why they occasionally struggle with social anxiety. They could find it more difficult to make friends than other people do, and they sometimes wind up the target of bullies. Additionally, these girls do not get the assistance and early intervention they require.

The Extreme Male Brain Theory² of autism, put forth by Simon Baron-Cohen in 2002, aims to explain the striking parallels between attributes typically associated with "maleness" in humans and traits linked to the autistic spectrum. According to his research, many of the characteristics linked to ASDs can be compared to an extreme version of "typical male" strengths and challenges. In the sphere of mental health, there has long been a prejudice that asserts that certain behaviours and characteristics, such as aggression and externalized symptoms, are fundamentally masculine. Internalizing symptoms, such as anxiety, belong to the feminine gender. Clinical observations reveal many women who receive their autism diagnosis in adulthood have had various other diagnoses including anxiety disorders, depression and mood disorders, borderline personality disorder, obsessive-compulsive disorder, and eating disorders³. Autistic women are more involved in "social-camouflaging" or "masking" of their autistic traits which is a major reason for this misdiagnosis. Social camouflaging is the use of strategies by autistic individuals to minimize the visibility of their autism in social situations. These strategies can involve masking autistic characteristics, for example by deliberately suppressing stimming behaviour in public (Hull L et al., 2017). Learning compensatory behaviours, such as nonverbal social behaviours, is a part of social camouflaging. Examples of this include making eye contact and developing scripts

² Simon Baron-Cohen suggests two dimensions for understanding human sex differences, "Systemizing" and "empathizing." According to psychometric definitions, the male brain is the cognitive profile in which systemizing performs noticeably better than empathizing, and the female brain is the opposite.

³<https://theconversation.com/autism-is-still-underdiagnosed-in-girls-and-women-that-can-compound-the-challenges-the-y-face-176036>

that may be used to direct interactions. Social camouflaging is a common aspect of the lived experience of autistic persons, especially among females, according to studies done for quantifying and exploring it in men and women with autism (Lai M-C et al., 2017). Masking can complicate social situations and can be detrimental to one's sense of self. Women who appear to be socially adept yet exhibit aberrant conduct are harshly criticized, even when the problems are due to missing or misunderstood social cues. They are aware that they may have unintentionally offended people, and they feel hurt and guilty about it, but they are unsure of why or how to put it right.

Pragmatically speaking, social groups are never adequately portrayed in the media as they are in reality. It is very hard for television and other media to accurately represent every facet of autism because there are many distinct forms and degrees of severity. The media can, however, make an effort to portray events as precisely as they can. However, there have been several instances where it has gone wrong, hurting the feelings of both the community members and their caregivers. The public understanding of autism gained momentum after the production of *Rain Man* in 1988 which contributed to a generalization that all autistic children have certain savant skills. Popular shows like *The Good Doctor* (2017-present) and *The Big Bang Theory* (2007-2019) bolstered this idea and made it seem benign or even flattering to persons with autism. The way media has overhyped different autistic traits without input from the autistic community and this lack of an 'autistic perspective' has led to faulty representations and misconceptions. The representation of disabilities, in general, was problematic and was not received well among self-advocacy networks. Personal narratives are one form of communication that provide the most truthful representations of autism, despite the way the media has altered how it is seen. Since the launch of YouTube in 2005, video blogs have skyrocketed in popularity as individuals share their in-depth opinions on a variety of subjects. The fact that these postings are very accessible, allow access to a variety of people who may otherwise be hard to contact and provide the opportunity for replication across research are a few of the major benefits of using this content. Additionally, it offers a chance to analyze interactions in the "real world" as opposed to only through experiments.

Thus, the current study aims to examine how gender discrepancies in autism have impacted the lives of autistic women by analyzing TEDx Talks delivered by them and tries to establish how these talks can lead to de-constructing existing collective memories of the same. For this study, the community feedback section of these videos is equally significant because a combined analysis of the talks and the autistic women who commented on them re-constructs a *La Memoire Collective* through the knowledge of experience and shared memories.

2. Method

2.1 Criteria for Video Selection

The following criteria were taken into consideration for selecting appropriate videos. First of all, the videos should have autistic women as the speakers since the study deals with gender differences in autism. It was important to select stimulating talks in terms of content, speaker's delivery, and proximity of the topic. The videos were chosen considering how they managed to deliver their lived experience with autism and its late diagnosis. The varied background of the speakers with regard to sex, age, ethnicity, and first language was an additional advantage since all the videos were TEDx Talks. Since there is still little research on the dating and relationship experiences of autistic women, videos that also covered this aspect were chosen. Apart from inclusivity, another criterion was that the videos need to be informative, although most Ted Talks have an educational undertone. Attention was given to sorting videos that do not place autism in a completely positive or negative light, because autism comes with both strengths and challenges. Ted Talks uploaded from 2017 to more recent ones till 2022 were considered. 5 such talks with a duration of fewer than 18 minutes were chosen for the study.

2.2 Current Study

The TEDx Talks analyzed for this study are exclusively by autistic women who got diagnosed in their adulthood and listening to them is crucial for subverting what was said about autism by people who are not specialists and do not have a lived experience. The keyword used for the search was "Ted talks by autistic women", which showed 22 results as of December 2022. Among these videos, five were carefully chosen considering factors like late diagnoses, racial diversity, and age. The common aspect which connects all the women in these talks is that all of them got their diagnoses not as a child, but later in their life after going through a protracted period of uncertainty, confusion, and struggle. All the selected videos have autistic women as speakers who made their presentations highly informative though they are sharing their personal journeys. The analysis was organized by opening a text file for every video and adding descriptive text, transcripts of video clips, and comments. At the same time, associations were made with theories and interpretations that surfaced while watching each Ted Talk.

3. Discussion

"Behind the Mask: Autism for Women and Girls" by Kate Kahle was organized by TEDx Austin College where she

talks about gender discrepancy in autism diagnoses. This discrepancy is the reason why she wants to encourage more research to be done on symptoms of autism in women and girls so that they can be more easily and accurately diagnosed in the future. In this talk, she advocates for early diagnoses which leads to a higher chance of that child receiving evidence-based treatment, which can help with better life outcomes. Kate narrates her lived experience as an autistic woman who received her diagnosis only at the age of 15 and was happy about getting it because all these years, she believed that she behaved this way because she was weird. She also details masking which includes “forcing eye contact, mimicking others’ expressions, behaviours, or gestures, or even memorizing scripts for small talk and common conversations” (TED, 2021, 7:04). She correctly notes that being a woman is a unique and difficult experience in and of itself. The extra challenges that autistic women encounter, but do not receive help for are also highlighted in Kate's discussion. She has trouble with the standards of female friendship, romance, menstruation, and remaining safe from sexual predators, in addition to her difficulties with social interaction as a woman. In a society that wants to project that gender is insignificant, she narrates through her lived experience as an autistic woman that gender does matter by highlighting the vast disconnect between the autistic lived experience of men and women. Though all autistic individuals are born autistic in this world, from birth girls are thrust into a more socially rigorous environment that increases the pressure to mask. Because Kate emphasizes how women are supposed to have more emotional intelligence and care more about their peers from a younger age, her talk appeals to both autistic and non-autistic women. This video's area for community feedback may be seen as a forum for participation where women can share their own problems and connect with one another because they have autism. Many comments expressed relief because the discussion was essentially a revelation for many of them. One of the comments read “I had no idea that hyper-emotional sensitivity was related to autism. Every day I discover more and more symptoms I have experienced since childhood and never had an explanation for. Thank you for spreading awareness to people with and without autism” (Meredith, 2021).

Carrie Beckwith-Fellow in her TEDx talk “Invisible Diversity: A Story of Undiagnosed Autism” shares her personal journey of autism diagnosis at the age of 35. Aware that a late diagnosis can cause issues with identity, relationships, and perceptions, she shares her post-diagnosis experience. She refers to autism as an invisible diversity because she never understood that a difference existed all through her life. She finds the labeling of autistic as ‘high’ and ‘low’ functioning to be inappropriate because though she is diagnosed as “high-functioning,” her autism is not mild. Carrie also tries to break the stigma that autistic people do not feel any emotions or connect with others. Concerning emotions, she says, “So I can feel it intensely, but I can’t name it” (TED, 2017, 5:29). Apart from masking, she elaborates on “stimming” which is crucial for her when it comes to communication. She adds that autistic people need to stim though society forces them to stop stimming. Starting from childhood, to her adulthood she received a series of misdiagnoses including bipolar disorder, and borderline personality disorder, and was even given electroconvulsive therapy. Mental health issues and mislabelling are recurring issues in an autistic woman’s life where professionals failed to understand them. Carrie’s story can be understood as a typical example proving how good autistic women are at masking their autism. The community feedback section of this video shows that Carrie’s talk inspired a lot of women to go for an official diagnosis. “I am crying listening to this, I’ve always wondered “what was wrong with me” and now I understand, I’m going to contact a doctor as soon as possible, I’m so grateful I found this video”, was a comment by Kianisjuan (2020).

Emmy Peach in her TEDx Talk “Unmasking the Stigma behind Autism in Females” gives the example of her brother who received an autism diagnosis at the age of 5 whereas she and her mother were diagnosed at a very later stage. She elaborates on the professional inefficiency when it comes to diagnosing women on the spectrum. Since her brother was diagnosed and was receiving counselling, she explains the stigma even from those who are professionals that “only boys have it” (TED, 2022, 0:43). The Female Autism Phenotype⁴ (FAP), a particular way in which autism is presented in females who do not meet the conventional diagnostic criteria for autism, is another topic she covers. She also raises the problem of women hiding their diagnoses in order to protect themselves from judgment by their peers. Emmy's presentation stands out since it includes information on the co-morbidities of autism, as she herself has both autism and ADHD (Attention- deficit hyperactivity disorder). She is able to convey how varied and multifaceted autism can be through the clarity of her words and expressions. She makes clear that despite increased awareness of autism and neurodiversity, the stigma persists. Even though Emmy's lecture was just recently recorded, the video has received a respectable number of views and comments, and many autistic women were moved by it to “unmask” or discuss their autism in greater detail.

“My Brain isn’t Broken” is a TEDx talk given by Tashi Baiguerra where she narrates her personal experience of

⁴ Female Autism Phenotype is the behavioural expression of autism more common in females which may be expressed in ways that differ from traditional autism diagnostic criteria. These include social relationships, relational interests, internalizing problems and camouflaging.

slipping through the cracks and not receiving the support she needed. The reason for this which she explains is the number of pervasive and harmful stereotypes about the autism spectrum. Many women like her do not fit into this stereotype, and for that reason nobody sees them. She also points out the strengths and challenges that come along with autism, and how her autism makes her insanely passionate about the things she cares about. She goes into detail on how difficult it is for her to deal with social circumstances, odd obsessions, and failed friendship attempts. She describes how she often hits herself and then loses her ability to function for hours. Many autistic women are motivated by Tashi's experience to speak out about their condition rather than hiding it.

“Women and autism: Towards a Better Understanding” is a TEDx talk given by Sarai Pahla where she delivers a manual for those who dare to date a woman from the spectrum. She was diagnosed with what used to be called Asperger's Syndrome at a later stage in her life. Her talk connects with other autistic women because she explains her everyday struggle with doing chores like putting an object correctly into the cupboard. She elaborates on her autism-related struggles and the fact that she tried for almost twenty years to achieve the so-called boyfriend-girlfriend status that she actually wanted to have attained in her teenage. As an autistic woman, maintaining eye contact was difficult for her, and she believed this aspect was very important in a relationship. She also touches on the issues of sensory overload and the challenges in developing physical intimacy. One of the comments from the video read that “You absolutely nailed down what it's like to be an Autistic woman. Nailed it. Your comments about dating and wanting to connect and wanting love really touched a nerve with me” (Brunette, 2018). This very comment itself is a validation that Sarai's talk has served its purpose of getting connected with another autistic woman who has traversed similar paths.

All these women speak of the detrimental long-term repercussions of masking, which have led to a number of mental health problems. The memories they share are about misdiagnoses, anxiety disorders, depression, and self-harm. From all these conversations, it is clear that these women's entry into the reality of autism is only more expressive once they have been given a diagnosis. As Rosenberg (2002) argues, being diagnosed articulates the individual experience with the social and is a rite of passage from uncertainty to a structured narrative. While expressing relief at finally understanding the disparities in their behaviour throughout their lives, these women describe a paradoxical relationship with their diagnosis. There was perpetual agony over not understanding what was going on and why they were feeling so uneasy. These women accepted their diagnosis, which aided in their transition from self-criticism to self-compassion and gave them a greater sense of agency.

According to Halbwach (1992), individual memories and collective memories can be identified as tools through which social groups establish their centrality in individuals' lives. The establishment of groups through collective memory enables them to distinguish themselves from other groups that may have diverse memories of the past or perhaps varying interpretations of the same events. Speaking of the lived experience in this context entails telling specific memories from a woman with autism in her life. An important component of identification with other autistic women is the lack of acceptance of autism traits among their friends and family. Another point of identification happens when these women realize that most of them received a diagnosis, not as a child. We see the development of hefty identifications when autistic women with similar experiences watch these shared videos. These autistic women live and re-inhabit everyday life with each talk that is created, distributed, and viewed. When other autistic women self-identify with this, it creates a collective identity in the experience of an autistic woman who had a late diagnosis. A social identity is developed based on shared memories and experiences. This identity collects experiences and strengthens the sense of belonging in the social sphere. Collective and personal memories help to shape social identity, which supports the idea of an individual's coherence and unity. In addition to this identification in autistic women, the study found that sometimes shared memories can create a sense of community and forge alliances. These women and other autistic women can organize their experiences and reconstruct their everyday lives through the act of narrating their lived experiences, which creates collective memories and fosters the growth of an affective community. According to Caldas (2003), from Halbwachs' perspective, the formation of shared memory occurs, above all, through affective affinities and joint trajectories and, thus, it presupposes an affective community.

The scenarios that guide daily life or are conjured up in the collective imagination affect the memories that make up the individual experiences of autistic women, making the narratives under analysis a collective and social phenomenon. Collective memories passed down through socialization are used to navigate individual memories when they are combined into a group. Collective memory refers to the memory of a specific group that bases its identity on memories of a shared past to which the group ascribes meaning rather than merely the mundane sum of various individual experiences. This shared past not only gives meaning to the present and opens to the future, but also allows the construction of differences between us and them (Halbwachs, 1992). The autistic women who have watched, shared or commented on these videos identify themselves as a mnemonic community that got informed and guided by these talks. Comments on these videos are candid personal reflections where autistic women reflect on their lived experience, their struggles, and challenges before and post-diagnosis.

The potential for the report to be viewed by others who have had the same experience and to create a network of sociability, albeit one that is digital, from this encounter is another crucial aspect of sharing unique experiences (Freitas & Gaudenzi, 2022). The unique scenario shown and presented in the videos can assist those who have had a similar experience in re-entering normal life both emotionally and practically. Many women relate to this because these speeches virtually entirely covered living as an autistic woman, including failed friendships and relationships, as can be seen in the comments section. There are women who commented about their meltdowns, anxiety issues, and how overwhelming it is to have “functioning labels”. Another aspect is that we can observe the production of an “authenticity aura” (Sibilia, 2008) in these contents, which is quite significant on it while not exclusive to this platform. As Steiner and Zelizer (1995) point out, collective memory is a process that is constantly unfolding, changing, and transforming. The process of shaping collective memory is neither linear nor logical, but dynamic and unexpected (Steiner & Zelizer, 1992). The talks given by these self-identified autistic women engage in the negotiation of collective memory by reconstructing the existing narrative of ‘boys only have autism.’

4. Conclusion

The common perception of autistic individuals and autism itself is frequently based on unreliable media representations, as is the case with many neurodivergent people and conditions. Autism affects individuals of all genders and sexualities, yet most media portrayals reinforce the white-male stereotypes. Without further support, autistic women are expected to complete their education, act like their neurotypical counterparts, and pick up social cues. This may cause individuals to conceal their behaviour, which would ultimately prevent them from receiving the necessary diagnosis and care. Thus, the present article attempted to analyze the lived experience of autistic women as narrated by them by making use of the possibilities of influential spaces like YouTube and Ted Talks.

Digital media, in particular, has brought to the fore the manner in which media materials can contribute to the formation of collective memories, with cultural artifacts being revived digitally and their meaning and purpose recast anew through digital recirculation. By analyzing the chosen Ted Talks, the article attempts to show how collective memory is constructed among autistic women who watch, share, and comment on these videos. As indicated, all the women in the analyzed videos primarily shared their lived experiences as autistic women, right from their diagnosis till their present life where they identify themselves as autistic women. The common aspect which connects all these women is that all of them wanted to highlight the gender discrepancy in autism diagnosis which prevented them from receiving adequate care. All the speakers in the selected videos highlighted both the strengths and challenges that come along with autism and effectively pointed out the issue of masking among autistic women. These videos show women’s narratives of what it is to be a woman with autism, how they experienced the subjective mobilization of the diagnosis, and the construction of identification between the women in these videos and the women who watch and comment on them. This paper has attempted to analyze narratives of both white and black autistic women but has left a gap for transgender and other non-binaries with autism. These intersecting identities are further complex and other studies should analyze their reported experiences.

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