



‘Even the Way I Make My Coffee is Autistic’: Meaning of Autism in the Lives of Middle-Aged Women prior to and After their Diagnoses

KREMENA NIKOLOVA-FONTAINE

SNÆFRÍÐUR ÞÓRA EGILSON 

*Author affiliations can be found in the back matter of this article

RESEARCH



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ABSTRACT

The aim of this qualitative interview study was to shed light on the meaning and experiences of autism in the lives of middle-aged women, prior to and after their diagnosis. The study was informed by critical disability studies and critical autism studies. Six women who all had shared their experiences in an Icelandic documentary about autistic women participated. The Interpretative Phenomenological Analysis (IPA) was used in data analysis. In retrospect the women described painful experiences from their youth and their struggles with meeting the demands of typical social and work environments due to their autistic characteristics and inaccessible environments. Personal and environmental dimensions uniquely interacted to mediate the women's exclusion in various situations. The women's late diagnosis made them revise and rewrite their past, emphasizing environmental aspects instead of assuming personal blame for the hardship they had endured.

CORRESPONDING AUTHORS:

Kremena Nikolova-Fontaine

Town of Hafnarfjörður, Iceland

kremena@hafnarfjordur.is

Snæfríður Þóra Egilson

Centre of Disability Studies,
University of Iceland, Iceland

sne@hi.is

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INTRODUCTION

Autism is defined as a neurocognitive condition characterised by difficulties with social interactions, reciprocity, flexibility, and processing of sensory stimuli (APA 2013). Autism is nevertheless not a stable diagnostic category, and adult identification did not occur until the 1980s (Lai & Baron-Cohen 2015). Prevalence of autism is considered to be higher in diagnosed men compared to diagnosed women, with a male-to-female ratio of four to one (Fombonne 2009). However, there is increasing evidence that this ratio is inaccurate due to many autistic girls and women going undiagnosed or misdiagnosed (e.g., Loomes, Hull & Mandy 2017). The female experience of autism has been somewhat ignored, as autistic women tend to be under- or misdiagnosed due to the male-dominated criteria (Bumiller 2008; Kirkovski, Enticott & Fitzgerald 2013).

According to Shefcyk (2015), female autistic behaviour often goes unnoticed for three main reasons. Firstly, because of the uneven male-to-female diagnostic ratio, autism research tends to be male-centric. Secondly, due to societal expectations for gender differences and traditional roles (Bargiela, Steward & Mandy 2016; Saxe 2017), autistic women often internalise their social problems, such as through symptoms of depression and anxiety, whereas autistic men externalise them by displaying hyperactivity and misconduct (May, Cornish & Rinehart 2016; Oswald et al. 2016). Autistic women are under greater pressure to use camouflaging strategies to fit in (Hull et al. 2017) and tend to do so more successfully compared with autistic men (Lai et al. 2018), contributing to their under- or misdiagnosis (Bumiller 2008; Kirkovski, Enticott & Fitzgerald 2013). Thirdly, autistic women oftentimes receive a late diagnosis due to their high frequency of co-occurring medical and psychiatric diagnoses (Lai & Baron-Cohen 2015); a deterioration of mental health may also be an implication of being late diagnosed. Having an autism diagnosis in early life can help women to understand why they feel different from others by enhancing their self-confidence about their unique identity and alleviating the pain of exclusion and mistreatment (Ryan & Räisänen 2008).

In Iceland, as elsewhere, most autism research has focused on prevalence and comorbidities, as well as on diagnostic and intervention practices in childhood. A recent Icelandic documentary, *Seeing the Unseen* (Ludviksdóttir & Kristjánsson 2019), presented by the Icelandic Autistic Society provided important insights into 17 autistic women's lives and their individual experiences of autism, daily challenges, and social difficulties. Inspired by this documentary, this study aimed to shed light on the experiences and meaning of autism in the lives of middle-aged women prior to and after their diagnosis. The following research questions were posed: 1) How do autistic women, who participated in the documentary, describe their lives prior to their diagnosis? and 2) How do these women make sense of their diagnosis and its effect on their lives?

THEORETICAL FRAMEWORK

This study is informed by the lens of critical disability studies (CDS) and critical autism studies (CAS). CDS emerged as an interdisciplinary field based on contributions of feminist, queer, postcolonial, and critical race scholarship (Goodley et al. 2019; Meekosha & Shuttleworth 2009). CDS tries to reframe ability in non-ableist ways, drawing attention to practices and knowledge which produce and reinforce normal/abnormal binaries (Campbell 2009), thereby marginalising, excluding, and often dehumanising disabled people. CAS supports autism as a diagnostic label and seeks the emancipation of autistic people as a neurologically different form of life (Woods et al. 2018). While CAS scholars do not always agree on issues and priorities, they all criticise the ableist theories that have produced and sustained harmful stereotypes about autistic people (Gernsbacher & Yergeau 2019; Milton 2012).

Davidson and Orsini (2013) identify three main aspects of CDS that are compatible with the theoretical direction in CAS: 1) challenging the power relationships of oppression in the construction of autism; 2) changing the public discourse and the negative stereotypes about autism; and 3) developing new approaches with emphasis on the highly individual nature of autism. Some autistic scholars have criticised CDS for lacking autistic authorship and claim that non-autistic scholars exhibit neurotypical bias by misinterpreting autistic people (Milton & Sims 2016). As an example, the book *Re-Thinking Autism* (Runswick-Cole, Mallett & Tamini 2016) provoked heated debates, as it questions the legitimacy of the autism diagnosis and challenges the status quo of neurodiversity due to a lack of genetic evidence for a brain difference (Guest 2019). Within CAS, there have also been lively debates, as some autistic scholars have criticised

leading CAS scholars for dismissing those who question the neurodiversity paradigm which argues that autistic minds are just different from non-autistic minds (Bolton 2018; Guest 2019).

THEORIES PRODUCING STEREOTYPES ABOUT AUTISM

The classic triad of theories about autism, presented in the book *Autism: Explaining the Enigma* (Frith 2023), describe autistic differences as a brain dysfunction and deficit. The first, the theory of mind deficit, claims that autistic individuals lack a natural ability to understand the feelings of other people (Frith 2003), which produced the hurtful stereotype that autistic people lack empathy. Lai and Baron-Cohen (2015) later pointed out that although autistic people may not read information about emotions from the expressions of others, they nevertheless display affective empathy, become upset, and want to help when information is provided about another person's suffering. The second theory, weak central coherence, presents autism as a difference in information processing and cognitive style, specifically in the context of noticing and memorising details (Happé & Frith 2006). The third theory, executive dysfunction theory, relates to the intense interests and stereotypical behaviour of autistic individuals. When their brain is overloaded with too much information, autistic people often use repetitive movements to calm themselves, which non-autistic people tend to misinterpret as a signal of boredom and inattention (Frith 2003).

Baron-Cohen (2002) presented the theory of extreme male brain, which is often discussed together with the triad of theories. It explains autism with excessive exposure to prenatal testosterone and changes in brain development, resulting in an intuitive understanding of mechanical objects and a preference for the physical world instead of psychological states (Frith 2003). Many autistic women claim that this theory shifts attention away from female needs (Jack 2012), and the autistic scholar Milton (2012) considers it a crude reference to autism, as it maintains the simplistic machine-like myth of autistic people in popular understanding.

The biomedical focus on deficits and dysfunction in the classic theories has influenced the public discourse and upheld the stigma against and exclusion and othering of autistic people (Holt et al. 2021). Furthermore, autistic people are blamed for their perceived social differences (Milton & Sims 2016) and are expected to fit into the non-autistic norms of social interactions (Crompton et al. 2020). Milton (2012) calls it the 'double empathy problem' because the fault for failure in communication is never one-sided and the non-autistic majority makes little effort to understand and accommodate the needs of the autistic culture.

IMPORTANCE OF AUTISM DIAGNOSIS AND DISCLOSURE

The diagnosis of autism, which is based on behavioural and communication differences, has been criticised by CDS scholars (Goodley et al. 2019; Runswick-Cole et al. 2016) because it reflects the ableist ideology that views typical minds and abilities as superior and those labelled with impairments as inferior and flawed. Similarly, Milton and Sims (2016) draw attention to the negative impact of having one's autistic identity pathologised. However, the importance of an autism diagnosis for increased autism awareness, acceptance, emotional support, and inclusion has also been stressed. In Iceland, as in many other countries, diagnosis is a prerequisite for receiving specialised services, accommodations, and support. A decade ago, the classification of autism was extended to a spectrum of similar conditions in the DSM-5 diagnostic system (APA 2013). Reportedly, this change aimed at providing an increased opportunity for diagnosis and access to services and counteracting stereotypes that primarily associated autism with being a white male and minimally verbal child (Botha, Dibb & Frost 2020). Nevertheless, adult diagnosis is still reported to be challenging due to lack of developmental history, use of camouflaging strategies, and high rate of co-occurring diagnoses (Lai & Baron-Cohen 2015).

A scoping review of the literature about perceptions and outcomes of autism diagnosis disclosure reveals that disclosure may lead to a better understanding and acceptance in society: 'changing the attribution of cause for behaviours from an undesirable personal characteristic to something related to autism beyond that person's control' (Thompson-Hodgetts et al. 2020: 19). However, some autistic people recommend selective disclosure or non-disclosure, depending on the context, due to the stigma still attached to autism which adversely affects people's attitudes towards them. Furthermore, a diagnosis disclosure does not provide instructions on how to support an autistic person due to their highly individual characteristics and circumstances (Thompson-Hodgetts et al. 2020).

An important aspect of autism awareness is information about possible gender differences. Studies show, for example, that autistic women exhibit less repetitive behaviour compared with autistic men (Hartley & Sikora 2009; Mandy et al. 2012). They also experience a higher frequency of sensory discomfort (Lai et al. 2011) and attention difficulties (Holtman, Bölte & Poustka 2007), worse sleep, and more mental health problems (Hartley & Sikora 2009). Lai and Baron-Cohen (2015) go as far as to acknowledge the existence of a female autism phenotype and suggest that health professionals are reluctant to diagnose women because of outdated myths associating autism with severe communication problems and savant skills. Accordingly, the social struggles of autistic women who can maintain eye contact, undertake small talk, and are perhaps married with children may be ignored.

Bargiela, Steward, and Mandy (2016) directed attention to the impact of gender norms in misinterpreting autistic behaviour in childhood. The late diagnosed women in their study reported that in elementary school, their quiet, passive, and compliant behaviour had been encouraged by teachers and their emotional struggles were ignored. In college, the social environment became more complex to navigate, and their differences were harder to conceal. The women's straightforwardness was misinterpreted as being rude and their 'literal and inflexible' thinking as being lazy, so they were often blamed for being bullied and reprimanded for not acting normal. Sedgewick, Hill, and Pellicano (2018) found that the biggest challenges for autistic women were their inability to form wide social networks, failure in conflict resolution, and unawareness of competitive group dynamics. The women also described the high anxiety that resulted from accidental conflict due to misunderstandings when interacting with non-autistic people. In another study by Sedgewick et al. (2019), autistic women reported being more upset by failure to navigate friendships and their consequential dissolution, as well as a greater vulnerability to exploitation, compared with their non-autistic peers. However, the autistic women often grew more socially confident and satisfied in adulthood.

Lai et al. (2018) reported that autistic women demonstrated more sophisticated camouflaging strategies (e.g., hiding one's autistic characteristics and presenting different roles in different social situations) compared with autistic men, but another study showed no consistent evidence of behavioural differences between genders (Hull et al. 2017). Camouflaging strategies can be so effective that other people may be surprised to learn of a familiar autistic individual hiding their true feelings (Tierney, Burns & Kilbey 2016). Such intensive self-monitoring and constant awareness of others' reactions can be physically and mentally draining, thus increasing the risk of mental health problems (Hull et al. 2017) and autistic burnout characterised by long-term mental, physical, and emotional exhaustion that builds over time, often recurring after stressful life events or transitions (Mantzalas, Richdale & Dissanayake 2022).

In a systematic review, Hawyard, McVilly, and Stokes (2016) found several challenges for autistic women in the workplace, mostly relating to communication, social interaction, and stress, together with negative mental and physical health. Similar aspects are highlighted by North (2021), who demonstrated how disability and gender intersect to create negative outcomes for autistic women in the workplace. Many employers remain underinformed about neurological differences and how the needs of autistic women may vary. They are consequently uncertain of the support that may be of benefit to their autistic employees.

METHODOLOGY

PARTICIPANTS

To recruit participants for the study, contact was made with the Icelandic autistic organisation, which consequently mailed an information letter to mature autistic women who had recently shared their experience in the documentary *Seeing the Unseen* (Ludviksdottir & Kristjansson 2019). Altogether six Icelandic women over the age of 40 responded and consequently took part in the study, one identified as queer. It turned out that all had received their autism diagnoses as adults—three of them after the diagnosis of their child. The women had completed educational degrees within a wide range of professional fields. One was fully employed, and the others were either partially employed or self-employed. Four resided in the greater capital area, where approximately 70% of the Icelandic population lives, and two lived in small towns in other parts of the country.

The data were collected from November 2020 to May 2021. Each interview lasted a minimum of 60 minutes. In line with participants' preferences and due to the pandemic, five interviews were conducted on Zoom. The sixth interview took place face-to-face at a location of the participant's choice. All interviews were conducted in English by the first author and recorded and transcribed with the participants' consent. Before the interviews, the authors watched the documentary multiple times to get insights into each woman's experience. Then, an interview frame with topics to be discussed was developed, highlighting the personal experience of living as autistic women, the meaning of the autism diagnosis, and their experience in relation to participating in the documentary. The interview frame nevertheless advanced as the interviews progressed. For example, the first two women brought up camouflaging and life satisfaction themselves, so these topics were addressed and discussed in the remaining interviews.

A strong need for predictability with autistic interviewees in qualitative research has been emphasised, such as by making agreements in advance (Rasmussen & Pagsberg 2019). Consequently, the interview frame was e-mailed to all participants before the interviews. The interviews started with simple, precise, and structured questions which were followed by more open-ended questions. A clear indication was given when the interview was coming close to the end. All recorded data was transcribed word-by-word by the first author, and both authors analysed the data. Guided by the framework of interpretative phenomenological analysis as described by Shaw (2010), the analysis started with descriptive summaries accompanied by notes about interpretative and conceptual ideas. A reflective diary was used to reflect on the descriptive summaries by identifying potential issues, misunderstandings, and contradictions. Next, the data were divided into major groups of important information and corresponding quotes. A list of all descriptive commentaries in one interview served as a base for comparison with the lists of the previous interviews and then with the next one. Organising a summary of quotes in each interview (index card) facilitated the analysis. Finally, all six interviews were analysed together. The entire list of descriptive commentaries was then grouped into clusters of main themes, subthemes, and smaller topics that corresponded to the research questions. These commentaries gradually became more interpretive and conceptual. The final analysis focused on what the women had in common and then nuances of idiosyncrasies were added. In the Findings, we focus on the women's voices and experiences, and in the Discussion, these experiences are scrutinised through a critical lens.

ETHICS

All participants were informed about the purpose of the study and willingly participated. They received an introduction letter and a written consent form before the interview, where they were informed about the aim of the study, the interview process, and their ethical rights. Each consent form was signed by the researcher and the participant before the interview took place. An emphasis was placed on trust and anonymity, such as by using pseudonyms for people and places. Nevertheless, the fact that the participants had openly shared their experiences of being autistic women in the documentary made them possibly more recognisable, to which they were made aware and acknowledged.

Our theoretical lens based on CDS (Meekosha & Shuttleworth 2009) and CAS (Woods et al. 2018) has methodological implications, as they demand reconsidering of conventional research practices and assumptions, and a commitment to self-reflexivity. We, the authors, have not been diagnosed with autism and do not have lived experience with the topic. The first author is a non-native Icelandic and a mother of an autistic girl. During the research, we strived to be reflexive and aware of our values, perspectives, experiences, and theoretical knowledge. As an example, we sought out the critical perspectives in the autistic academic community (e.g., Bolton 2018; Guest 2019; Milton 2012), because prior to this research, much of our knowledge was derived from non-autistic scholars and the assumptions we have absorbed from living in an ableist society (Hammell 2022).

FINDINGS

The findings are organised into three main themes. The first theme focuses on the women's lives prior to their diagnosis. The second theme focuses on the meaning-making of their autism diagnosis. And the third theme focuses on their current sense of autistic pride and identity.

All six women vividly described their struggles earlier on when they did not know anything about autism. They outlined how their autistic characteristics, such as their 'straightforward personality' and 'lack of flexibility', had complicated their lives due to the lack of understanding, accommodations, and support. The lack of societal awareness about autism maintained their devalued positions as 'not fitting in' and being 'an alien'. Difficult experiences with maintaining good mental health were also shared, which they attributed to not being aware that they were autistic or to being misdiagnosed.

Reflecting on their past, the women described a lack of connection with peers in childhood, especially with other girls during their teenage years. Negative social interactions had made them sceptical of friendships later on, and only one had maintained friendships since her college days. One woman claimed, 'No one should go through what I went through as a kid, not knowing.' Another one explained that in her youth, 'Autism was not a word, it was not an option. Somehow it came into my world as a concept after 40. ... It should have been obvious when I was two years old.' The third claimed, 'I don't think I was invisible at all. The symptoms were already there in many ways all along, but nobody thought about autism.'

Memories of abusive relationships and being bullied were shared: 'I was so trusting and naive. Manipulative people find it easy to control me. Gaslighting works easy on me. I was taken advantage.' One participant described a strategy of defending her self-esteem by being a top student: 'because then they [her peers] had to respect me' and 'they would leave me alone and not bully me'. Simultaneously, her self-protective strategy had unintended consequences, because 'nobody thought that the kid with high grades [could] have a problem', so she got no support for her social challenges. She claimed having been terrified of 'peer groups' and that girls were her 'nemesis'.

In retrospect, all the women described environmental features which had negatively affected their well-being. Sensitivity to light (e.g., blue LED lights), smell (e.g., perfumes producing a burning sensation in the nostrils), and sounds (e.g., noise from TVs and vacuum cleaners) was central in their accounts. As described by one woman, 'a huge factor in my life which affected everything'. Another participant described a strong sensitivity to visual patterns of colourful forms, especially when under stress. For instance, walking along paths with paving stones of different colours, shapes, or sizes could produce a physically uncomfortable experience, which had also disturbed her mental focus at times. When temporarily overwhelmed by such sensory triggers, the women had typically reacted by disconnection from social contact. Gradually, they had developed coping strategies, such as forcing themselves to overcome light and noise sensitivity or simply avoiding specific places and situations. Sensory sensitivity escalated under social stress, as one participant explained, 'I can handle face-to-face interactions, but it is difficult to interact with more than 1–3 people at the same time.'

To reduce stressful sensory exposures, the women emphasised their strong need for a structured and predictable environment, which had even affected their choice of partners and relationships. One claimed, 'Grand surprising gestures, no, I hate it. Small scale, candle-light dinner, okay, I can live with that. But throw me a surprise birthday party, I hate that.' Another woman shared a key aspect of her marital satisfaction as having a non-autistic partner who had always been respectful of her autistic need for private space with headphones at home. Needing 'alone time to sleep properly' was also specified.

However, the most challenging aspect of being autistic related to social demands because of what they described as their difficulties with understanding and following unwritten rules and group dynamics. Much of their narratives centred around the traumatic experiences they had encountered at their former workplaces. Making 'social errors' and 'provoking conflict situations unintentionally', combined with co-workers' limited knowledge about autism, inflexible attitudes from superiors, and lack of adjustments in the physical and sensory environment, had repeatedly led to their loss of employment, which had had a traumatic impact on their self-esteem and even mental health.

They also explained how temporary situations of being overwhelmed by sensory overstimulation had been misinterpreted by their non-autistic co-workers as a 'rude lack of interest' in communication

instead of a physical disposition. In two women's opinion, lack of optional training for improvement of social skills had complicated their situation further. One woman pointed out that job interviews are generally 'not advantageous for autistic people', as employers 'may get the wrong impression by talking to them'. The opinion that autistic men get more job accommodations compared with autistic women because of different gender expectations in society was also expressed.

Positive aspects of autism about work were also shared. A participant described herself as a reliable professional who was appreciated for her precise work ethic in terms of showing up on time, being in charge, and having very clear expectations. She added, 'When I think I did 100% job, I put in 200% effort.' Another participant, who had found a sense of belonging in a scientific environment, described feeling proud when her supervisors told her that they wanted to employ more women and unique thinkers like herself. This was a pivotal moment for her, understanding that 'perhaps there is nothing wrong with me. Perhaps there is something wrong with society.'

The three women who had managed to maintain good employment and even leadership positions reported using camouflaging skills throughout the years, appearing as non-autistic up to the point that people doubted their diagnosis. One claimed she had been like 'a chameleon', going through life using multiple masks in different contexts. Another woman said, 'I have been masking for so long, that I don't know where it starts or ends. I think I do it automatically without thinking, except when I am in a group where everyone is autistic, then I just let go.' But masking came at a physical and emotional cost and involved 'hard work'; the women were often overwhelmed to the point of burnout afterward. When she reached the transitional period of menopause, one woman claimed, 'I simply don't have the energy to mask anymore. I just cannot be bothered.' The other three participants did not relate to the concept of masking and wondered whether their inability to use camouflaging strategies had contributed to the social difficulties and isolation they had endured.

'I AM NOT UNHAPPY ABOUT BEING AUTISTIC. I JUST WANT TO BE AWARE OF IT'

All participants claimed that self-education about autism had helped them understand the hardships they had endured earlier on. Acquiring this knowledge had been a turning point in their lives, enabling them to make sense of their past and rewrite their stories. The extreme emotions of self-blame and internalisation for experiencing social difficulties, which they had repeatedly encountered, gave way to a sense of liberation and more constructive explanations. One woman described it as 'climbing on top of a mountain and screaming, you know: "This is a thing! People have it!"' She compared the benefits of having a diagnosis to having 'an anchor'. Another participant said that the information about autism as a neurological difference had helped her to make peace with losing jobs in the past: 'So then I first understood that I was not to blame.' Only one woman reported having mixed feelings about her diagnosis. She claimed that being diagnosed late in life was perhaps harder compared to being younger, because adults were less flexible in adjusting to new situations. In her experience, 'It [self-acceptance] was a gradual thing: it was not an epiphany kind of thing.' Her initial reaction to the diagnosis had been a feeling of being let down because autism was unfixable. However, her perspective had changed, and she now firmly believed that the focus should be directed at fixing society instead of trying to fix herself. After receiving a diagnosis, she also got the 'courage to ask for accommodations' at her place of work. Two other women reported 'initial fears' and 'some kind of prejudice' when their autistic children were diagnosed, but their attitude had changed into a total acceptance by the time of their own diagnosis.

The participants emphasised the importance of early access to autism diagnosis. Although they acknowledged the fact that autism as a spectrum had only been recognised in the diagnostic criteria since 2013, they would have wished that professionals were more aware of autism in their childhood. They also considered the diagnostic criteria to be still very male-centric. One pointed out the usefulness of blogs by other autistic women offering a list of typical indicators of female autism. All six women called for increased autism awareness in society and that a female phenotype or a more 'internalised version' of autism be acknowledged by health professionals. Earlier on, two women had received mental health diagnoses, which they attributed to being misdiagnosed. One of them had embraced her autism diagnosis with a positive attitude right away because it led to improved supports and services, whereas her mental health diagnosis had not been as useful: 'I was very relieved because, you know, I already had this diagnosis of [mental health condition], so it was a great improvement of my situation.'

The women described their participation in the documentary as an important opportunity for improving autism awareness and directing attention to autistic female issues. Subsequently, the women received invitations for autism discussions and related events. Disclosing their diagnosis in public led to improved self-confidence. As one explained, 'It felt more natural to have autism and to acknowledge and admit it to other people.' Altogether, the participants reported receiving only supportive feedback, such as praise from non-autistic strangers, questions from parents, and gratitude from undiagnosed individuals.

'EVEN THE WAY I MAKE MY COFFEE IS AUTISTIC.'

At the time of the interviews, all six women considered being autistic as an integral part of their identity. They expressed a strong autistic pride and did not want to be 'cured of autism', which they considered as neither an illness nor a disability. One woman described being autistic as the most natural part of herself. She reflected on a moment in the making of the documentary:

When [the director] asked me to tell her about my autism, I looked at her and my mind went blank. My first reaction was, yeah, to describe my autism! And I thought, how can you describe eating? How do you describe breathing? How do you describe not being autistic, because it is so ingrained into me?

Several remarks were made where the women associated their best qualities with autism. One woman compared her rare type of singing voice to being autistic, which was her metaphor for having a unique talent. She added jokingly, 'Even the way I make my coffee is autistic.' Another woman revealed that she 'utilised her autistic pattern-thinking as an artistic gift' in the creation of patterned designs. Their passionate interests were described as a strength of expertise on the job market as well as the attention to detail and the ability to hyperfocus on an important subject of interest. The women's need for calm, structured, and predictable environments, which had brought about problems at work earlier on, was now emphasised as an advantage of self-reliance in working from home.

Although none of the women had been aware of being autistic when they had made their educational and career-related decisions, they all explained that, in hindsight, their choice of occupation had been influenced by their autism. One considered her literary profession to be a perfect fit for autistic people in the solitary job of freelancing, and three claimed that the health professions and social sciences were a good fit for autistic people due to their non-judgmental attitude and desire to understand the social world. Although their bluntness had provoked numerous conflict situations and was compared to 'living with PTSD' in a constant state of perceived 'random attacks by strangers', all six highlighted their aversion towards dishonesty as an admirable trait. The women also emphasised that their social difficulties did not reflect a lack of empathy. One claimed, 'It is a big misunderstanding that autistic people don't have empathy, we just have a different kind of empathy.' She further explained that her interest in history was motivated by a desire to understand the nature of suffering and humanity. Having a strong sense of justice was linked with the potential of being autistic as well as an attraction towards other honest and fair people who valued integrity. One woman claimed that 'the prejudice within the autistic community is low' and 'we generally identify with strange people'. She continued, 'It has always interested me, people on the margin of society. I love, you know, the book characters who are usually the sorcerers and witches, and the people who look at society from the outside.'

After claiming 'autistic people are the loneliest people on the planet', another woman explained that autistic people were not antisocial but simply needed the company of other autistic people to develop a sense of friendship. She further clarified, 'It doesn't mean that we are better. It's like we are tuned into a different radio station. It's very strange, we feel some kind of a connectedness that you sense ... chemistry.' All six women were active in autistic support groups and online communities, which they considered an integral part of their well-being and a safe space to connect with others. One explained, 'We don't mask. We can say things and not worry, it is very freeing. [When I am together with other autistic women] I don't use a fraction of the energy, which I use in other interactions for the same duration of time.'

Through participation in the documentary, the women discovered a kind of sisterhood with the other participants because of their shared experiences as autistic women. Although they enjoyed social interactions to a varying degree, they had all discovered a sense of belonging in the autistic community.

This study explored mature women's experiences of living with autism before and after receiving an autism diagnosis. Inspired by CDS and CAS perspectives, the findings are discussed in more detail below. In retrospect, the autistic women described painful struggles with meeting various social demands because of their undiagnosed autistic characteristics and negative consequences of living in a predominantly non-autistic world, such as burnout and poor mental health (Mantzas, Richdale & Dissanayake 2022). Their diagnosis, albeit late, helped them make sense of their experiences and recognise how ableist norms and expectations (Campbell 2009) had shaped their past and pressured them to fit in by appearing and functioning as 'normal' as possible. Although the women claimed to have been 'visibly autistic' at an early age, the criteria were different back then (Lai & Baron-Cohen 2015). Due to the male and childhood lenses that have characterised how autism is understood, their challenges were not recognised and consequently not acted on.

A high rate of sensory sensitivity has been described as the most common autistic feature among women (Lai et al. 2011), and all the participants had experienced discomfort from physical and sensory environments due to their sensitivity to light, sounds, smells, or patterns. Nevertheless, most challenges occurred in social interactions due to the women's difficulties with navigating neurotypical norms and expectations. This again interacted with a lack of understanding, flexibility, and support. Thus, personal and environmental dimensions uniquely interacted in forming and sustaining the women's difficult experiences, not the least at their workplaces. Unintentionally provoking conflict situations had repeatedly led to the loss of employment due to social and cultural forces, such as employers' lack of knowledge. Hence barriers were not removed, and accommodations were not implemented, which had negative consequences for their sustained employment and overall well-being. This aligns with North's (2021) findings that autistic women who do not conform or exhaust quickly by trying to fit in may render themselves an inconvenience or troublesome to their employers and colleagues. Milton, Martin, and Melham (2017) highlight that employers should be receiving training to provide more autistic-appropriate strategies when recruiting, guided by the tenets of universal design.

The women explained that, in hindsight, their occupational choices had been informed by their undiagnosed autism. They also emphasised that autistic people could be great employees because of their many talents, such as their non-judgmental attitude, empathy, reliability, passionate interests, and pattern perception. The theoretical explanation by Lai and Baron-Cohen (2015) about autistic affective empathy aligns with the women's self-reports as having perhaps 'a different kind of empathy' than non-autistic people. The women linked their empathy to a heightened sense of truthfulness and social justice, an aversion towards dishonesty, and heightened vigilance towards being the target of a lie (Atherton et al. 2019).

Typically, non-autistic people blame the fault in communication on the autistic individual, and the classic triad of autism theories has reinforced the public attitude toward autism as a brain dysfunction and autistic people as lacking empathy (Milton 2012; Gernsbacher & Yergeau 2019). Social exclusion is thus reinforced by negative autism stereotypes of being awkward, difficult, and angry people (Wood & Freeth 2016). Nevertheless, failure in communication is a two-way street, as social interactions are always a reciprocal exchange (Milton 2012). Thus non-autistic people must show understanding and appreciation for autistic people's interests and knowledge so that they feel welcome and relaxed (Lai & Baron-Cohen 2015).

The unconscious use of camouflaging strategies as a way of overcoming social challenges has been described as a characteristic among autistic women (Lai et al. 2018). The three participants who claimed to have used masking extensively to fit in and form connections had managed to maintain good employment and leadership positions throughout the years in contrast to the others. They nevertheless stressed how draining their use of masking had been at the cost of their physical and mental health. Although autistic burnout was not mentioned by all the women, much of their descriptions of their long-term mental, physical, and emotional exhaustion fit well with the core features of autistic burnout as described by Higgins et al. (2021); Mantzas et al. (2021); and Mantzas, Richdale, and Dissanayake (2022).

Interestingly, although the women were critical of the lack of understanding and support in their environment, a few of them attributed some of the problems they had encountered

throughout the years to themselves, such as not having had enough social skills, having needed social skills training, and provoking conflict situations, as they did not understand social rules and group dynamics. To some extent, these women appeared to have internalised ableist views (Campbell 2009) which positioned themselves as in need of fixing. In addition to masking, this internalisation may have possibly contributed to the health problems they had endured. A recent Icelandic study demonstrated the negative effects of internalised ableism on the health and well-being of disabled young people (Jóhannsdóttir, Egilson & Haraldsdóttir 2022). Similar to the findings of that study, the autistic women's internalisation took place through interactions with external structural arrangements, which maintained and reinforced their devalued positions, such as being stereotyped as strange and deviant. However, the women's experiences were neither fixed nor stable, and positive experiences were certainly shared.

Although the negative impact of pathologising one's identity as autistic has been pointed out (Milton & Sims 2016), as well as the downside of the diagnosis possibly becoming people's main public identity (Thompson-Hodgetts et al. 2020), this was not the case in our study. All six women cherished their diagnoses and described autism as the most natural part of themselves, such as breathing and making coffee. In fact, the diagnosis had liberated them from earlier self-blame, as aforementioned. Through their autism diagnosis and finding a community of like-minded people, the women experienced self-acceptance and improved self-esteem, which contributed to their current strong sense of autistic pride. This is consistent with studies that show that autistic people often find autistic spaces comforting, as they provide feelings of connection, recognition from others, and positive accepting relationships (Crompton et al. 2020; Gernsbacher, Stevenson & Dern 2017; Milton & Sims 2016).

LIMITATIONS

Only six women participated in this study, and there was much homogeneity in our sample, such as mature age, late diagnosis, and participation in a documentary. All six were Caucasian and native Icelanders, had completed university degrees, and were verbally fluent. Thus, we make no claims of generalising the findings.

CONCLUSION

This article explored the life experiences of autistic women before and after receiving their diagnosis. In retrospect, the women described painful experiences from their youth and their struggles with meeting the demands of typical social and work environments. The women's late diagnosis made them revise and rewrite their past, emphasising the effects of ableist environments instead of assuming personal blame for the hardships they had endured. The women's experiences as put forward in this article can help combat the psycho-emotional disablement autistic people often experience by reframing stereotypical views about autism and emphasising self-acceptance, self-advocacy, and inclusion (Mantzalas, Richdale & Dissanayake, 2022; Milton & Moon 2012).

Our findings suggest that in order to make workplaces respectful of individuals displaying social non-conformity and enable the use of autistic talents (Lai & Baron-Cohen 2015), greater attention should be placed on adjustments to physical and sensory spaces, fostering relationships between employers and employees, and discussions about diversity. Accommodations at school and work need to be customised to different personality characteristics and the fact that the nature of autism is highly individual (Davidson & Orsini 2013). Teachers should be mindful of autistic behaviour and social exclusion among female students, as the quiet, passive, and compliant behaviour of autistic girls may be regarded as socially acceptable in line with tacitly and explicitly shaped gendered dimensions of society (Bargiela, Steward & Mandy 2016).

The ableist ideas about autism as a deficit and behavioural dysfunction, which surface in biomedical autism theories, have upheld much of the stigma, exclusion, and othering of autistic people. Possibly, they are so deeply embedded within our culture that we may not be able to recognise them. And if such ideas are not recognised, they will be neither contested nor resisted (Hammell 2022). It is imperative to aim for a more inclusive society, where human diversity—people with different qualities, abilities, and limitations—is celebrated and where autistic women feel included and safe.

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AUTHOR AFFILIATIONS

Kremena Nikolova-Fontaine

Town of Hafnarfjörður, Iceland

Snæfríður Þóra Egilson  orcid.org/0000-0002-7578-5207

University of Iceland, Iceland

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