The quest for acceptance: A blog-based study of autistic women's experiences and well-being during autism identification and diagnosis

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Running header: Blog-based study of autistic women’s experiences

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**Abstract**

Background: While studies have found that autism is underdiagnosed in women and that autistic women have poorer wellbeing outcomes compared to men, less is known about autistic women’s experiences with self-identification or diagnosis or how they feel such experiences affect their mental health.

Methods: We explored autistic women’s experiences of coming to recognise and understand themselves as autistic. We used data collected from blogs written by autistic women about their diagnostic or self-identification experiences. We were particularly interested in wellbeing, and how this contributed to, was affected by, and interacted with the identification and diagnostic process. We used thematic analysis to explore and document experiences described in blogs from twenty blogsites (representing the views of 23 autistic women).

Results: Acceptance was a central issue. We developed themes of self-understanding and self-acceptance, being understood and accepted by others (including peers, clinicians, and others in the autism community), and the exhaustion resulting from trying to be accepted and be understood. These issues arose both when going through the diagnostic process, and after receiving a formal diagnosis.

Conclusions: Diagnosis and identification may have both positive and negative effects on autistic women’s well-being, with women often describing difficulties following diagnosis as stemming from facing male stereotypes of autism. We consider the implications of our findings for clinicians, researchers and those that work with autistic women.

**Community Brief**

Why was this study done?

Research shows that autistic women are under-recognised and under-diagnosed. This can lead to a lack of support. Other research indicates worse mental health outcomes in autism. Exploring the perspectives of autistic women could help us understand how diagnosis may relate to mental wellbeing.

What was the purpose of this study?

This study examined the experiences of autistic women. We focused on wellbeing, mental health, and the role of diagnosis. We wanted to gain insight into how to support autistic women to achieve positive wellbeing.

What did the researchers do?

The researchers read blogs from 20 blogsites, reflecting the views and experiences of 23 autistic women. Women were either self-identifying or clinically diagnosed. The researchers then used a qualitative research technique called “thematic analysis” to summarize what women often said about well-being and diagnosis.

What were the results of the study?

Acceptance and feelings of belonging were important. We developed three themes: 1) self-understanding and self-acceptance, 2) being understood and accepted by others, and 3) exhaustion. Study participants felt that diagnosis often helped them understand their needs and be kinder to themselves. Diagnosis also helped women make sense of what had happened to them in the past. Finally, it helped them connect with a community, and improved relationships. However, stereotypes of autism affected women’s own acceptance of their diagnosis. In some cases, feelings that they did not fit an autism diagnosis led to imposter syndrome. They described the struggle for acceptance, before and after their autism diagnosis, as exhausting. They felt this exhaustion came from trying to hide their difficulties or having to explain why they did not fit stereotypes.

What do these findings add to what was already known?

These findings support research which has identified high levels of exhaustion in autistic women due to trying to hide their difficulties and conform to societal expectations. Our findings suggest that acceptance is important for autistic women’s wellbeing after their diagnosis. Facing a lack of acceptance from others could impact on women’s self-acceptance. This could disrupt the positive effects a diagnosis has for women’s wellbeing.

What are potential weaknesses in the study?

In their blogs, women were remembering their past experiences. Therefore, time may have impacted these women’s views, and changed what is important to them. Our sample was limited as it did not include women who publicly identified as having intellectual disabilities, it only contained adult women (mainly aged 20-50 years), and it did not include non-binary individuals. Experiences of autistic women who write blogs may be different from those of other autistic women.

How will these findings help autistic adults now or in the future?

We suggest that when women seek diagnosis, acknowledgment of the difficulties they have faced coping without the recognition of being autistic is crucial. Clinicians should be aware that women may mask their difficulties, and they should avoid minimising underlying problems. This study suggests that challenging the stereotypes associated with autism and educating professionals about autism in women is highly important. Women may benefit from support after diagnosis that helps them to manage experiences of being told they do not appear autistic, or do not fit people’s expectations of autism.

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Autistic women are consistently under-recognised, under-diagnosed, and thus unsupported.1, 2 Meta-analyses of screening studies in the general population indicate that although more men than women meet the criteria for autism, there are a substantial number of women who, if assessed, would receive an autism diagnosis. However, these women have not been identified, and have thus not got a formal clinical diagnosis.3 This particularly occurs for women and girls without co-occurring intellectual disability,4 perhaps because they are less likely to attract clinical attention. Furthermore, even where women and girls do receive a diagnosis, this is on average later than boys and men,5-7 meaning that autistic girls and women go without appropriate timely support.

Multiple factors likely impede the diagnosis of autistic women and girls. Firstly, diagnostic instruments have a gender bias, having been developed with largely male samples, and because autistic girls and women’s presentation often differs to boys and men.8 This leads to challenges in being recognised as being autistic, and potentially experiencing disbelief or stigma from those around them when they receive a diagnosis (see Huang et al9 for review). Partly because of these experiences and responses, and partly because of the sense of self-knowledge that can come from being diagnosed as autistic,10 the self-identification and diagnostic processes can be highly emotional for autistic people. This is especially the case for those coming to the realisation in adulthood, who may be reframing their life histories through an autism ‘lens’, a process described as ‘biographical illumination’.11

The increased presence of camouflaging amongst girls and women on the spectrum may further hamper clinical recognition of autism. Autistic people report camouflaging for a variety of reasons, including wanting to manage differences between their natural behaviour and that of neurotypicals, to manage the demands of social situations, and to reduce conflict between their authentic self and societal attitudes.12 Camouflaging is considered an important feature of the female autism phenotype.13 Our current paper centres on women’s experiences, but it is important to note that autistic people of all genders camouflage, and we should be wary of perpetuating a stereotype that camouflaging is specific to autistic women and girls.14

While camouflaging in women and girls may allow many to “pass” in a neurotypical society, these coping strategies also have consequences: late-diagnosed autistic women report that camouflaging is emotionally draining and creates confusion over one’s identity.15 Tint and Weiss16 discuss the “hidden hurt of maintaining the mask” regarding autistic women’s experiences. The consequences of camouflaging include anxiety, stress, and exhaustion, with camouflaging levels having been shown to positively correlate with mental health problems for autistic women17 (though Cage and Troxell-Whitman18 and Hull et al19 report associations between camouflaging and mental health that are not affected by gender, suggesting this should not be considered a phenomenon exclusive to women and girls).

Mental health is a priority in autism research, for all genders: autistic individuals are at a higher risk for comorbid mental health problems than the general population.20 Considering women specifically, Sedgewick, Leppanen, and Tchanturia21 found that autistic women are more likely to have anxiety and depression than non-autistic women, whilst autistic women and non-binary individuals showed higher rates of mental health conditions than autistic men. Suicide rates in autistic women are higher than in other clinical and non-clinical groups22: self-reported camouflaging measures significantly predict their psychological distress, and for a specific sub-sample of women with very high camouflaging scores, these also predicted suicidality. Females are more likely to report internalising problems, whilst males more often have co-occurring behavioural problems.13

Concerningly, the women least likely to be diagnosed as autistic appear to be those at greatest risk of mental health difficulties: highest reported rates of depression are seen in autistic adults without intellectual disability.23 Autistic people without an intellectual disability are at greater risk for death by suicide than the general population, and than autistic people with a co-occurring intellectual disability.24 Recognising autistic women could have important implications for addressing their co-occurring mental health problems (if not preventing them), as timely recognition as autistic can inform treatment approaches. For instance, adjustments are needed to cognitive-behavioural therapy approaches for treating anxiety in autistic people.25

Overall, the current literature paints a picture of widespread under-detection of autistic women, mental health problems faced by autistic people, and the potential interaction between these two issues. Given this, examining autistic women’s perception of the relationship between their mental wellbeing and getting an autism diagnosis may provide insight into how best to support autistic women to achieve good mental health. We thus aimed to explore the diagnostic/self-identification experiences of autistic women, focusing on their well-being and mental health. Our overarching questions were: what impact does identification and diagnosis have on women’s mental health, and what impact does mental health have on women’s diagnosis and identification?

One way to understand the relationship between autism diagnosis, mental health, and wellbeing is to look at this in autistic women's own words. Qualitative health researchers are using blogs,26 and blogs offer access to naturalistic qualitative data.27 As yet, there has been limited use of blog material by autism researchers. However, the autistic community has an active, growing online community, and the internet provides a positive tool for autistic people to connect with others, articulate their experiences, and advocate for acceptance.28, 29 For example, Yoon Kim and Bottema-Beutel30 analysed the blog posts of nine autistic bloggers to investigate online narratives about stimming, and Welch et al31 analysed 40 blogs written by autistic bloggers to examine embodiment in autism. It is clear from these projects that blogs by autistic people can offer a rich “insider view” of the autistic experience. However, such studies are few, despite blogs offering unique and interesting opportunities: unlike qualitative data collected via a traditional interview or survey, the data is created by bloggers outside the influence of a research team. The blogs were not created in response to researcher questions but represent things important enough to the bloggers for them to want to write about. Analysing such media offers a complementary way to study people’s experiences, with less direct impact of the researcher (though they have an important role in selecting and synthesising this data). A secondary aim of this paper was thus to test the utility of blogs written by autistic individuals for researchers interested in their experiences.

**Method**

In addition to the methodological details here, to supplement this paper and support researchers who might want to explore using blogs for future research, we have created a document generally introducing this blog-based approach, including considerations for ethics and research question fit (see Supplementary Materials).

*Blog search strategy*

We searched for blogs using MetaCrawler, using the search terms “autism blog”. MetaCrawler is a metasearch engine which aggregates the results of what would have been returned from multiple separate specific search engines, thus offering better web coverage.32 Our pre-agreed criteria to decide which blogs were included in our analysis were that the blogger a) was writing from a first-person perspective (i.e. not written by non-autistic parents); b) identified as female; c) was over the age of 18 years; d) wrote in English; e) discussed the process of realising they were autistic and pursuing a diagnosis. We anticipated that some women would face barriers to obtaining a formal diagnosis, and we could not check the veracity of bloggers saying that they had been clinically diagnosed; thus, we decided that bloggers who self-identified as autistic would also be included. We included blogs found on blog compilation sites or that were referred to through another site. We excluded any blogs where the author team felt there was doubt as to whether the blog should truly be considered “in the public domain”: no blogs required memberships to forums or passwords to access. The included blogs were the first blogs returned from the search that met our inclusion criteria.

When considering saturation (see 33), we decided ahead of the search that an initial set of 15 blogs would be selected, and then we would examine whether more than five new codes were generated for the 12th-15th bloggers. Were this to be the case, we would search for and select a further five blogs. As more than five new codes were generated in the analysis of these blogs, a further five bloggers were added (the next five blogs returned that met criteria). After coding the 17th-20th blogs, no new codes were generated, and we considered our saturation rule met.

*Blogger characteristics*

Table 1 summarises the characteristics of the included bloggers, according to information disclosed in the blogs. All but one reported being formally diagnosed as autistic. One blog was a compilation of views from four women: we refer to them as Blogger 16.1, 16.2, 16.3, and 16.4. This particular blog also included the views of an autistic person who was non-binary: we decided as a research team not to code the sections of content from this person, as they did not meet our pre-specified inclusion criteria. Of the bloggers who stated they had been diagnosed, all but two had been diagnosed in adulthood; several reported being diagnosed after their child was diagnosed as autistic. Most bloggers reported mental health problems, most commonly depression and anxiety. While most bloggers did not describe their ethnicity in their own words, from images and information on the blogs we believe most were white.

*Coding and analytic procedure*

Our approach follows that outlined by Braun and Clarke34 for reflexive thematic analysis. This approach is flexible with regards to epistemological approach: we took a largely semantic and critical realist approach. Critical realist approaches separate structures and mechanisms (the real) that generate events (the actual), which may then be experienced and perceived (the empirical).35 This allows the experiences of individuals, and their reports, meanings and reality to be fully recognised. Applying an inductive approach, we generated codes and themes from our data (though previous literature on camouflaging allowed us to readily detect this phenomenon). Following initial coding, codes were reviewed by the author team, and blogs re-read to ensure all relevant data had been coded. Codes were grouped and developed into themes, initially by creating a hierarchy to group similar or related codes. We reviewed and discussed candidate themes amongst the author team, with consideration given to counter-examples and accounts that challenged our candidate themes, prior to arriving at our final thematic structure. During our analysis, we sought to ensure that the themes developed reflected the views and experiences of all our bloggers, and that quotes represented a range of individuals.

*Ethical considerations*

The University of York’s Psychology Department’s ethics committee approved our project. We applied the guidance of the British Psychological Society for Internet Mediated Research36. We did not contact the bloggers, as we took a non-intrusive approach: however, as noted above, we were careful to check that there was no indication that they considered their writing private (indeed, many explicitly stated they wanted to raise awareness about their experiences as an autistic woman). When considering the possible identification of the bloggers, we took a “moderate disguise” approach to the quotes included in the results37, meaning that we use pseudonyms (i.e. Blogger 10), and do not refer to the bloggers’ specific sites, but the quotes are verbatim from the blogs.

*Positionality of the researchers*

All members of the author team identify as women. The author team included an autistic researcher who was key in the coding of the data and theme development. The author team included university academics who have supervised autistic students of all genders. One author conducted her thesis on the experiences of friendships of autistic women. The author team thus included lived experience of autism, experience supporting autistic students, and academic expertise in autistic people’s social experiences.

**Results**

A central issue in the bloggers’ experiences was acceptance, including being understood and feelings of belonging. We developed three themes: self-understanding and self-acceptance, being accepted and understood by others, and exhaustion. The bloggers struggled for self-acceptance and understanding of themselves, and wanted to be accepted by others, first as a person who functions in the neurotypical world, and later as a “truly” autistic person. Breakdowns in understanding and acceptance (either directed toward the self, or from others) impacted their wellbeing, creating situations in which bloggers were vulnerable or mistreated. The tensions of trying to be accepted and understood led to exhaustion, an emotion that appears in all stages of the diagnostic journey, from before bloggers are aware of their autistic traits to after their formal diagnoses.

We further expand on our themes below. Figure 1 visually represents our themes, and includes proposed links between our themes and sub-themes. Text in bold in the sections below highlight sub-themes, for ease of linking with our Figure. Supplemental Tables 1 and 2 contain additional quotes, organised into the ways in which acceptance and understanding promote well-being, while breakdowns in acceptance and understanding risk well-being.

***Self-understanding and self-acceptance***

**Diagnosis helped bloggers make sense of what happened to them**. Written from a post-diagnostic/identification stage, the blogs are themselves a means for the bloggers to articulate their self-understanding, in light of getting an autism diagnosis. Throughout the blogs, women’s diagnoses had a powerful explanatory role, and was used to make sense of their previous difficulties. **Diagnosis helped the bloggers understand their problems and be kinder to themselves**, freeing them from believing they were dysfunctional and reducing feelings of inadequacy. Their new diagnoses allowed the bloggers to seek appropriate services which positively impacted their wellbeing.

*The relief and empowerment I felt when I was diagnosed and finally discovered what “was wrong with me” were overwhelming…It literally gave me a second life. [Blogger 5]*

However, many also experienced feelings of regret, particularly wishing that they had known sooner, as **not knowing had led to self-esteem/identity problems.** One recurrent symbolic reflection of this was that many of the bloggers wrote a letter to their younger self. These letters to their childhood selves also appeared to be an interesting representation of “making sense” of what happened to them, an exercise in self-understanding.

While for many, diagnosis brought increased self-understanding and acceptance, this was not universal. For some, **feelings that they did not fit the autism diagnosis led to issues with imposter syndrome**. Indeed, one blogger felt her specific diagnosis did not represent her, feeling that textbook descriptions of autism did not fitwith her experiences. For other bloggers, ongoing problems with self-acceptance were partly fuelled by the lack of acceptance from others and feeling like a fraud.

*When I finally told the people around me about my diagnosis, the range of responses ran from skepticism to "Oh, I suspected it years ago."... part of me is still sure that one day someone will point at me and say "faker!" [Blogger 4]*

***Being accepted and understood by others***

When reflecting on their childhoods, bloggers reported difficulties with friendships, being bullied or ostracised, and being taken advantage of. It was clear that **striving to fit in had been painful and exhausting,** and **not knowing about their autism had left them vulnerable.** Feelings of anxiety and disorientation arose due to feeling like others were experiencing a different reality to them: their undiagnosed autism left them with no framework for understanding why others experienced the world differently.

*Being an undiagnosed autistic can feel like the whole world is gaslighting you. From being told not to be silly, the lights aren’t hurting you... you’re being told every day that your lived experience isn’t real. There have certainly been times that I have doubted my sanity. [Blogger 2]*

**Lack of professional knowledge and misdiagnosis** had negative consequences. Some bloggers were misdiagnosed with other mental health conditions. With a non-autism diagnosis, their difficulties were interpreted according to these incorrect labels. The bloggers reflected on their experiences of unsuitable therapies; for some, these treatments left them with even worse mental health.

*Misdiagnosis left me vulnerable to the protocols and biases and stigma of, in my case, manic depression/bipolar... I felt tied to the diagnosis I had and even though my heart knew it wasn't right, my rigid thinking made me cling to it for far too long. [Blogger 16.4]*

*Although I was in therapy for PTSD and Dissociative Identity Disorder, I became discouraged. No matter how hard I struggled to “normalize” my emotional regulation, something always felt “off” inside*. *[Blogger 15]*

**Diagnosis improved relationships with others and fostered connections with communities,** reducing feelings of being an outsider. For some, not only did diagnosis bring a sense of belonging within the autism community, but also a sense of purpose and belonging within the neurotypical world, for example by improving communication within relationships and at work.

*Today I can say that our household and family is stronger than ever. My husband and I have a wonderful marriage because of – not in spite of- our differences. Learning to communicate in a neurotypical-neurodivergent relationship has led to a happier household and a greater appreciation for human diversity [Blogger 17]*

However, feelings of belonging post-diagnosis did not go unthreatened. Indeed, **fears around being accepted as truly autistic impacted bloggers seeking a diagnosis** at all. Bloggers were concerned that the diagnostic criteria only identify a person as autistic if they are male, have academic impairments, or are a child. This deterred some women from seeking assessment.

*My years of masking, coupled with an apparent high level of ‘functioning’, and an inability to ask for help, meant that persuading my GP to refer me was too anxiety provoking. … I had heard stories of women being refused referral due to eye contact with the GP…[Blogger 7]*

Even after a diagnosis, the bloggers **faced** **stereotypes about autism**, including other people questioning their diagnosis, and assumptions about their characteristics and abilities: one blogger was met with surprise that she could drive, and that she was a Christian. The challenge of the “rightness” of their diagnosis was unsettling for some bloggers, and was experienced as a rejection from a community they expected to be accepted by. Being faced with these stereotypes and lack of acceptance as “truly” autistic led to problems with self-acceptance: the feelings of “not belonging” turned inward, creating imposter syndrome.

*I feel like they are saying I'm fundamentally different from a LOT of other people with autism, the REALLY REAL PEOPLE WITH AUTISM, probably. I feel like I'm being kicked out of my own disability. [Blogger 9]*

***Exhaustion***

Struggles with wellbeing were present throughout the blogs, and were linked to the breakdown of self-acceptance and acceptance from others. Camouflaging and **striving to fit in was exhausting**, and a trigger for mental health problems for several of the bloggers.

*My chameleon skills were a double-edged sword: I could appear fairly "normal" for stretches of time, but they also drained me completely... I became so many different people that I felt I'd lost any sense of my own identity. [Blogger 4]*

For some, **breaking points lead to identification**;when bloggers broke down from the continued strain of trying to cope, these moments were catalysts for finally recognising that they were autistic. However, the diagnostic process itself was also anxiety-provoking, and as noted above **fears delayed some from seeking a diagnosis,** and women faced a **lack of professional knowledge** about their autism. Following years of camouflaging, showing the “real person” to a clinician (to obtain a diagnosis) required conscious vulnerability on the part of bloggers.

*When you have worked so hard to hold yourself together for so long, it is not easy to submit yourself to a process. We often worry that assessors are trying to trick us, to catch us out [Blogger 7]*

Even post-diagnosis, the bloggers reported having to explain themselves repeatedly, due to **not fitting autism stereotypes,** which disrupted the process of self-acceptance (noted above). This created a space in which autistic women felt they did not belong anywhere – they were neither neurotypical women, nor “properly” autistic.

*It felt exhausting to explain over and over again what me being autistic really meant, how it aﬀected me, why I was diﬀerent to the stereotypes but that didn’t mean I was less autistic [Blogger 2]*

**Discussion**

We sought to understand further the experiences of autistic women, and the interplay of their diagnostic journeys with their mental wellbeing. Our results centred around acceptance, specifically self-acceptance, acceptance from others, and exhaustion from breakdowns in acceptance. The lack of timely recognition as autistic contributed to the mental distress experienced by many of the bloggers. The diagnostic process itself also posed threats to blogger’s wellbeing, and while a formal diagnosis brought relief for many, autistic women still faced stereotypes and continued to feel that others required them to justify their diagnoses. While there are certainly benefits to being diagnosed, there are unfortunate parallels between the lack of acceptance and understanding earlier in life due to not being neurotypical, and a continued lack of acceptance and understanding later in life, due to being autistic and a woman.

Our findings complement previous studies on the experiences of autistic women, in that this population report high levels of exhaustion, and that attempting to camouflage their difficulties contributes to emotional difficulties and mental fatigue.15,16 The accounts of the bloggers also resonate with the review written by Zener,38 which states that a diagnosis brings mixed feelings of relief and validation, but also grief when women look back on missed opportunities. Also in agreement with our analysis, they argue that diagnosis can lead to new self-understanding and a sense of belonging, and a chance to develop self-acceptance, as mentioned in Tan’s concept of ‘biographical illumination’. 11 Indeed, previous findings from autistic adults note the relationship between personal acceptance, acceptance from society, family, and friends, and individuals’ stress and depression, in that greater acceptance leads to reductions in stress and depression.39 Our own interpretation is that the extent of the positive aspects of diagnosis on women’s wellbeing depend on the level of personal acceptance and acceptance by others. Furthermore, in their description of autistic burnout, Raymaker et al 41 state that “chronic exhaustion” is a feature; “exhaustion” was also our word of choice for capturing the difficulties experienced by the bloggers. Under potential solutions and strategies for avoiding or mitigating burnout, Raymaker et al40 list “Self-knowledge” and “Acceptance and social support”, which complements our findings. The study by Raymaker at al40 includes people of all genders: highlighting that experiences of exhaustion are unlikely to be specific to autistic women.

Our current analysis adds to these previous explorations by highlighting the important role that acceptance has in autistic women’s wellbeing, even after formal diagnosis. We have documented the ways in which this acceptance is threatened, including by continued facing of autism stereotypes, and how this disrupts the positive feelings of being understood and belonging. Our findings align with those of the Huang et al9 scoping review regarding adult experiences of autism diagnosis, further emphasising the importance of recognising and countering the stereotypes autistic adults face. Indeed, Botha et al41 argues that it is the stigma of others towards autistic people which is problematic, rather than being autistic itself.

Our work adds to a body of evidence that education about the female (or internalising) presentation of autism is needed not only for professionals who work with children and young people. In agreement with Zener38, we would emphasise the need for training and education in adult mental health services. Professionals involved in the diagnosis of autistic women should be mindful that the process may be emotionally stressful. Years of being undiagnosed may have led to camouflaging difficulties: the diagnostic process requires these strategies to be given up or revealed, leaving women feeling vulnerable. Some women may not even be conscious of their camouflaging behaviours.42 Diagnostic models in psychiatry are currently deficit-based: people are expected to show impairments to meet the criteria.43 This framework is at odds with the neurodiversity model, which argues that “disordering” autism can be harmful to an individual’s self-esteem, and argues for an approach that celebrates autism’s differences and unique strengths.44 While there has been some consideration of what the neurodiversity movement might mean for psychiatry,45 it seems unlikely there will be widespread change soon, considering that autistic and other neurodivergent people continue to face challenges with recognition of their unique needs and experiences within healthcare systems.46 Thus, we suggest that when women seek diagnoses, being aware that the presentation of a woman’s autism may be filtered through a highly developed mask is crucial for women to feel their underlying problems are not being minimised.

Challenging stereotypes associated with autism is also important: as illustrated by the bloggers, autistic women have many skills and successes that others may assume an autistic person would not. Being met with surprise or scepticism about your life is upsetting. Practically, our results have implications for post-diagnostic support for autistic women. Specifically, we suggest such support actively considers the impact of consistently being told they do not “seem autistic”, and how this may feed into feelings of imposter syndrome, and affect women’s self-understanding and self-acceptance. Creating resources or forums for women to unpack these experiences could help to overcome the negative impacts of these experiences.

This is one of few studies to use a blog-based approach to explore the experiences and views of autistic people. Overall, we would recommend such an approach to other autism researchers, but this design does bring with it some important limitations. Firstly, the data are retrospective. Some bloggers were reflecting on experiences from many years ago. While the research questions of our project centred around the views of the women themselves, and what was salient and important to them, it is possible their views may be different immediately post/prior to diagnosis (most of our bloggers wrote about five years later). Future studies might consider a longitudinal design, following women through their diagnostic experience and beyond.

One strength of the blog approach is that data are naturalistic and reflect what is important enough to the women themselves for them to decide to write about. However, we noted for some bloggers, almost all their past experiences appeared to them to be explained by their being autistic. This highlights the centrality of the autism diagnosis to these women’s self-understanding, but it could be that other important factors about their lives are not captured. Research projects working with blog data can only use what is written about: future researchers should consider the importance of veracity and the impact of potential omissions.

A further important limitation is who is likely to be represented in these blogs. We are missing the perspectives of older adults and adolescents. We did not note whether the women who wrote these blogs disclosed any diagnoses of intellectual disability. However, by adopting an approach in which we study the blogs written by autistic people, we should be mindful that this approach will likely lead to a biased sample that does not represent the whole of the autistic population. Autistic women with intellectual disabilities may be less likely to write a blog, meaning their experiences would not be represented.

While our search criteria would have allowed for the inclusion of transgender women, we do not believe any of our bloggers were transgender. Non-binary individuals were also not considered here. We posit that the issues of acceptance may be just as important if not more so in the experiences of non-binary and transgender autistic individuals. Indeed, a recent study by Hillier et al47 suggested that LGBTQ+ autistic individuals faced multiple minority stressors. Their participants described others’ lack of knowledge about autism and non-heterosexual orientations and non-binary gender identities. They also described experiences of rejection from the LGBTQ+ community due to their autistic traits, and from the autism community due to their sexual or gender identity. This double rejection has parallels to the experiences of the women in our own paper, where they faced rejection from the autism community due to not fitting a stereotypical portrait of autism. Together both our own and Hillier et al’s research highlights the need for more research into experiences of rejection from the autism community.

It is important to note that diagnosis in adulthood is not exclusive to women, and it is possible some themes and issues identified here also apply to men’s experiences. Some insight can be gained from the work of Lewis et al48: these researchers investigated reported barriers to getting an autism diagnosis as an adult. They report that women show higher agreement for barriers such as “Concerns I will not be believed”. This suggests that at least some issues are reported more frequently (if not exclusively) by women. However, while we centre our recommendations on services and supports for women (given that our data came from women’s experiences), we would encourage clinicians and practitioners to be wary of falling into patterns of thinking that these are issues exclusive to women and cannot also be seen in autistic people of other genders.

***Conclusion***

To conclude, our analysis of blogs written by autistic women highlight the role of acceptance in their wellbeing, as they progress through from not recognising or understanding their autism to identification and in some cases to formal diagnosis. The potential positives for women’s well-being of a formal diagnosis may be reduced by the expected or actual challenges required to get that diagnosis, and the lack of acceptance as autistic even after receiving a clinical diagnosis. Our project is also proof-of-concept for using blog-based approaches for researching the experiences of autistic individuals.

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**Authorship confirmation statement**

We confirm we are the sole authors of this paper.

**Author(s’) disclosure statement(s)**

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| Table 1: Summary of Blogger Characteristics | | | | | | | |
| ID | Diagnosis | Age range at time of diagnosis | Period of diagnosis | Year of blog entries included | Country of origin | Mental health problems disclosed in blogs | No of blog posts (included) |
| 1 | AS | 30-39 | 2010-2014 | 2015 | UK | Suicidality, anxiety (undiagnosed) | 7 |
| 2 | ASD | 30-39 | 2010-2014 | 2016-2020 | UK | N/A | 5 |
| 3 | AS | 20-29 | 2010-2014 | 2011-2013 | UK | Depression | 3 |
| 4 | ASD | 30-39 | 2010-2014 | 2016-2018 | Australia | Depression, anxiety, ADHD | 2 |
| 5 | AS | 50+ | 2010-2014 | 2012 | USA | Depression, anxiety | 1 |
| 6 | SI | N/A | N/A (Self-identifies) | 2011-2012 | USA | Depression | 2 |
| 7 | ASD | 40-49 | 2015-2020 | 2016 | UK | Anxiety | 1 |
| 8 | AS | 30-39 | 2000-2004 | 2012 | Canada | Depression, anxiety | 1 |
| 9 | PDD-NOS + AS | 5-11 | 1995-1999 | 2010-2011 | USA | Anxiety | 3 |
| 10 | AS | 0-4 | 1995-1999 | 2018 | USA | N/A | 1 |
| 11 | Autism | 50+ | 2010-2014 | 2014 | USA | Depression, anxiety, other non-specified | 1 |
| 12 | Autism | 30-39 | 2010-2014 | 2017 | USA | Eating disorder | 1 |
| 13 | Autism | 30-39 | 2015-2020 | 2015-2016 | USA | Depression | 2 |
| 14 | AS | 30-39 | 2005-2009 | 2018 | USA | N/A | 2 |
| 15 | Autism | 40-49 | 2010-2014 | 2018-2019 | USA | Depression, PTSD, DID | 2 |
| 16.1 | AS | 20-29 | 2010-2014 | 2016 | USA | Depression | 1 |
| 16.2 | Autism | Unspecified | Unspecified | 2016 | UK | Other non-specified | 1 |
| 16.3 | Autism | Unspecified | Unspecified | 2016 | USA | Depression, anxiety | 1 |
| 16.4 | Autism | 40-45 | Unspecified | 2016 | USA | Other non-specified | 1 |
| 16.5 | Autism | In childhood | Unspecified | 2016 | USA |  | 1 |
| 17 | ASD | Unspecified | 2015-2020 | 2019 | USA | Depression, anxiety, bipolar, ADHD | 2 |
| 18 | ASD | 40-49 | 2015-2020 | 2020 | UK | Other non-specified | 4 |
| 19 | ASD | 30-39 | 2010-2014 | 2019-2020 | USA | N/A | 3 |
| 20 | Autism | 40-49 | Unspecified | 2019 | USA | Depression, anxiety | 2 |

ASD = Autism Spectrum Disorder; AS = Asperger’s Syndrome; PPD-NOS = Pervasive Disorder Not Otherwise Specified; SI = Self-identifying; ADHD = Attention Deficit Hyperactivity Syndrome; PTSD = Post Traumatic Stress Disorder; DID = Dissociative Identity Disorder.

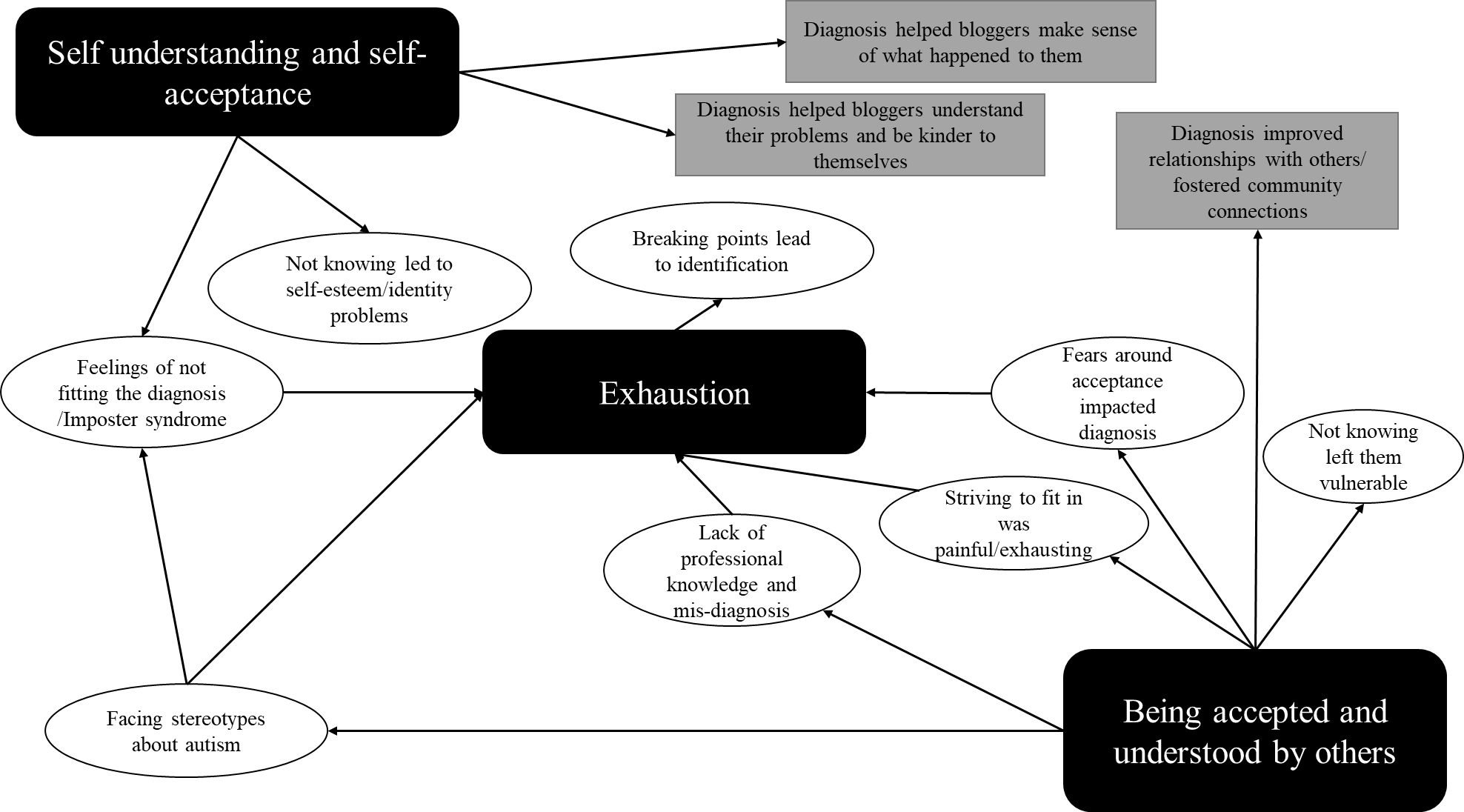


Figure 1: Thematic map. Black boxes indicate the major themes of self-understanding and self-acceptance, being accepted and understood by others, and exhaustion. Grey boxes indicate sub-themes that facilitated wellbeing. White ellipses indicate sub-themes that threatened well-being and may contribute to exhaustion.

**Supplementary Materials**

**Guidance, further resources and “lessons learned” about blog-based approaches**

Here we provide some further resources, notes and reflections about using blogs for research. To help future researchers who might want to use this approach themselves, we also provide details about the decisions we took for our current project.

***For a brief introduction to research using blogs:***

For researchers new to this approach and just interested in hearing more about it, we recommend a good place to start is a recorded talk by Helen Snee on blog analysis (accessible at: <https://www.methods.manchester.ac.uk/themes/data-collection/blog-analysis/> ), along with this accompanying paper1. We note that the term “blog analysis” might be a little misleading, as you can actually apply a variety of different analytical approaches to blog media, including thematic analysis, but also content analysis.

***Strengths and limitations: “should I do a blog-based study?”***

Researchers should consider the pros and cons of this approach, specifically as they relate to their desired research question. For further reading, we would recommend Wilson and colleagues examination of this approach for health sciences research2. This is an article about how blogs are getting used for research in a particular field. Although very much written with the health sciences in mind, we found it useful for considering some of the limitations and issues are around using blogs in research. Here, we note a few of our reflections about the strengths and limitations of this approach.

*Pros:*

**Naturalistic:** Blogs provide unobtrusive and “natural” narratives. By this, we mean that the data is not gained in response to researchers’ questions: the participants (bloggers) themselves decide what to write about, and are not influenced by the question being asked, or the presence of a researcher. Participants might be more candid on their blogs than, for example, when questioned by a researcher who may be perceived as having power over the participant, or representing a certain view.

**Available:** Arguably, blogs may provide comparatively easy access to the perspectives and experiences of groups that may be harder to recruit for a survey or interview study. This availability however very much depends on what kind of blogs you need. For example, if you are interested in a very rare population, there may be no, or very few, blogs in existence written by these people. It is worth doing some preliminary searches (ahead of your formal ones to gather your actual data) to check that there exist blogs that would meet your inclusion criteria.

*Cons:*

**Verifiability**: Simply put, this is the issue of not being sure that the bloggers are who they say they are, or that the experiences recounted happened as the bloggers describe them. We would argue however that this can also hold true for other research designs as well: a participant in an interview study could also describe something differently to how it happened, or in extremis lie about who they are.

**Fit to your research question:** This is the potential cost of the naturalistic nature and availability of the data: you are trying to fit pre-existing data to your research question. There might be a lot of content in the blogs that is not relevant to your research question (depending on how broad/specific your research question is: if your question pertains to the broad experience of a particular group, you might decide all blog content written by this group can be considered relevant). You will need to think about how you will deem material relevant or irrelevant to your question. Questions that are more specific may be better suited to an interview or survey study, in which participants respond to specific questions.

***Ethical issues***

The article by Helen Snee1 (also above) includes consideration of the ethical issues of blog research. We also found the British Psychological Society’s guidance for online/internet-mediated research3 useful. Here we list some particular things to consider.

**Local ethical review:** Even if no direct contact is being made with the bloggers themselves, projects may well still need review by local ethical committees. Do not assume otherwise.

**Consulting the community:** If the research team does not include a member of the community that the research question is centred around, researchers might want to consider consulting the community before embarking. This can be a useful process for checking whether the research team have thought sufficiently carefully about how bloggers may feel about having their material used: does the research question serve the needs of the community? We did not do this consultation process, but it would be something we would consider doing in future.

**Assuming assent:** Simply stating that a public blog is in the public domain and therefore “fair game” for researchers is not acceptable. In our current project, we discussed what indicators would suggest a blogger would not want their work to be included in research (e.g. any mentions of privacy, password requirements for access, etc). For example, one blog we found during the initial search mentioned that they had decided this blog had become too personal and that they were starting a new blog somewhere else to be more anonymous. This was enough for us to decide not to include the blog in our current project. We found this article by Eastham4 useful: it contains some flow diagrams for helping to decide when someone likely would not want their blog included in an analysis.

**Anonymity and quotes:** It is commonplace to use quotes in qualitative reports to help illustrate points and lend credibility to an analysis. These will be able to be searched if readers want to find the original blog. This is not necessarily a problem, but it should be considered whether this is acceptable for the research at hand: the level of anonymity should be considered in relation to risk to participants (i.e. bloggers) themselves. For example, a project looking at criminal behaviour might be deemed higher risk if bloggers are identified. This might also a consideration if your research study would include minors. In this case, you might not use direct quotes but instead paraphrase/deliberately alter some identifying details. Bruckman5 outlines high, moderate and light disguise approaches to quotes which researchers can examine and consider which best suits their project.

***Searching for blogs***

The searches we ran to gather our blogs were separate from any initial scoping searches (as mentioned, there are helpful to know that blogs exist that would meet your criteria, but we would recommend demarcating them from the formal search you document in your Methods section).

We felt it important to have our inclusion and exclusion criteria agreed before running the search to gather the data to be used. This was to protect the search process from bias: we wanted to avoid including or excluding material based on any preconceived ideas about what we would find.

We used MetaCrawler to search for blogs: the benefit of using MetaCrawler is that it aggregates what would have been returned if you had run the search on separate specific search engines (e.g. Google versus Yahoo versus Bing).

Keep careful documentation of the searches run, dates searches were run etc. We found it easiest to work serially through the returned blogs, and documented how many were rejected and for what reason (for us, this was usually because the bloggers were men, or parents, or did not include discussion of our required topic “diagnosis”).

***Handling the blog data***

We downloaded blog posts and imported them into NVivo for coding. Doing this approach again, we probably would set up a more standard approach to documenting the demographics of the bloggers themselves. For example, starting with the “About me” page, and then adding details depending on what was covered in the blogposts included. We ended up having to return to the blogs later in some cases to check details: having a standard approach from the start would save time.

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| ***Supplemental Table 1: Ways acceptance from self and others improves wellbeing– Example quotes*** |
| **Diagnosis helped bloggers understand their problems and be kinder to themselves**  *Once I was diagnosed, I was able to look for more targeted kinds of therapy with providers who accepted and understood my autism. I grew as a person, and I learned more about relationships and how to manage and enjoy them at work and in my personal life. [Blogger 20]*  *Since learning I am autistic, I have been able to rearrange my life in ways that help me deal with the sensory overload, anxiety, and other problems that I have always experienced. I have been given names for all these challenges, and instead of thinking of myself as “just really bad at being a person”, I can identify why something isn’t working well for me and try to adjust things so that I can cope better. [Blogger 4]*  *Self-diagnosing, and later formal diagnosis has kicked off a process of self-acceptance, understanding, and allowing myself grace, which I had generally previously denied myself. [Blogger 16.3]*  **Diagnosis helped bloggers make sense of what happened to them**  *There were a lot of ‘ahh!’ Moments to look back on! [Blogger 1]*  *I would imagine myself as a little girl, having been misunderstood, or suffering sensory pain, or needing to stim, or getting things wrong, and I just wanted to go back and tell her that I finally knew why. I wanted to hold her and tell her that one day she would know, that it would all make sense. [Blogger 2]*  **Diagnosis improved relationships with others/ fostered community connections**  *I was able to figure out how to let the neurotypicals in my life know what I needed. In fact, even in my prayer to my Creator, I make a request: “Ok Lord, listen up. You made me autistic and that is just fine. But if you want me to do something, I do not want to hear some soft voice hinting around at it. Please just come out and tell me what you want done and how you want me to do it! Thank you.” FYI: I told my bosses the same thing. [Blogger 15]*  *It is really, really good to be able to talk to other autistic people about things. [Blogger 3]*  *Remember when you were younger you felt you were a fairy, dropped in the wrong world? That you felt your wings were lost, and you would search, always search for your fairy folk? ... And when your older, you find your fairy folk. They are called Autistics. [Blogger 1]* |

**Tables of example quotes by sub-theme**

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| ***Supplemental Table 2: Breakdowns in acceptance and understanding from self or others risks wellbeing – Example quotes*** |
| **Striving to fit in was painful/exhausting**  *I did my best to try and ﬁt in and the resultant masking of my autistic traits played havoc with my wellbeing. [Blogger 18]*  *It was like being an actor on stage, without break, for hours and hours every day. And I became so many different people that I felt I'd lost any sense of my own identity. [Blogger 4]*  **Not knowing led to self-esteem/identity problems**  *…I began to gaslight myself. I’d tell myself that my reaction wasn’t real. I was being stupid or attention seeking…Without the self-knowledge I became my own worst enemy... I told myself how useless I was for experiencing the world wrongly. [Blogger 2]*  *Despite having always been odd, and never fitting in on any meaningful level, I had never considered that there might be a reason for this. I just thought I was a bit crap! [Blogger 7]*  **Not knowing left them vulnerable**  *I was being taken advantage of and should have cried but thought they ‘loved’ me so would believe anything... At the age of fourteen I fell pregnant. [Blogger 1]*  *I think one of the biggest dangers to autistic girls is being trained out of trusting our own sense of danger. [Blogger 16.1]*  **Lack of professional knowledge and misdiagnosis**  *The lack of knowledge around ASD means they may be diagnosed incorrectly even if they are receiving help. This was the situation I ended up in. A lifetime of masking and acceptable quirks had lead me to my breaking point. Like many autistic women, I received a diagnosis of anxiety, depression, bipolar II, and social anxiety. [Blogger 17]*  *It* [camouflaging] *erodes my identity because I’m not sure which bits of me are truly me. If you ever share doubts about your identity with mental health professionals, it can indicate various psychiatric conditions and personality disorders. …Once a label has been given every trait, behaviour and experience may be interpreted as part of that labelled disorder – this further erodes the sense of identity and creates a sense of being damaged or ill. [Blogger 18]*  **Fears around acceptance impacted diagnosis:**  *Only if you can prove your weaknesses can you be given a diagnosis… In a world where you have spent a lifetime doing your best to mask and hide those things, and focus on your positives, that can be a traumatic experience [Blogger 2]*  *I was also worried that if I started to talk about me, by removing the masks and the constructs, there was a risk I would crumble. It was too risky... The fear of being labelled faulty or damaged, rather than autistic, and of our needs not being taken seriously, is very real. [Blogger 7]*  **Feelings of not fitting the diagnosis /Imposter syndrome**  *No wonder I tend to prefer to call myself bad brains and insane in the membrane and Magikarp zombie waste of space. It seems obvious I belong in the Autistic community, and I even have that treasured thing: a fairly early diagnosis…but I know that I would be said to have "grown out of it" or been misdiagnosed, by any reasonable medical professional…[Blogger 9]*  *I still struggle with imposter syndrome, with feeling like my successes are fake… I don't consider having autism as a success or a failure so much as something that just 'is,' but I feel like a phony. [Blogger 4]*  **Facing stereotypes about autism**  *It has been almost a year since my diagnosis and I still get people who don’t believe me. [Blogger 13]*  *…I’d started to think of it as old news that I was autistic. I’d started to settle in to living as a whole person, without an emotional double life…“But you’re not autistic.” Which is where my brain froze up. Because honestly? I don’t know what else I am. [Blogger 3]* |