



Coláiste na Tríonóide, Baile Átha Cliath  
Trinity College Dublin  
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Ionad na Tríonóide do Dhaoine le Míchumair Intleachta, Scoil Oideachais  
Trinity Centre for People with Intellectual Disabilities, School of Education

## So Now What? Exploring the Post-Diagnosis Experiences of Late Diagnosed Autistic Women



Juliet Cabraja, Junior Sophister PPES, Trinity College Dublin

Supervisor: Professor Michael Shevlin, School of Education, Trinity College Dublin

Project funded by the Laidlaw Foundation, participants located with the help of Trinity College Dublin's Disability Service



## **I. Introduction**

As research on autism has become increasingly inclusive, the predicted ratio of men to women with autism has fallen from 15:1 to 4:1, or 2:1, depending on the consulted source (Eaton, 2018, p. 16 ; Honeybourne, 2016, xiii). Different academics have proposed various reasons for this disparity in the diagnosis rate, such as the relatively high rate of masking, or attempting to hide autistic traits, among autistic women. Masking can be described as the process of becoming “social chameleons,” to borrow a term from Victoria Honeybourne (2016, xi). Others critique the DSM-5, a diagnostic manual for autism, for its frequent inability to sufficiently identify autistic women (Honeybourne, 2016, 24). Participants in this study claimed a factor in the delay of their diagnosis was comparison to autistic men whose experiences and presentation differed from their own. Issues such as these reproduce and strengthen this gender gap and result in women “[needing] to display greater difficulty in ASD symptomology, adaptive behaviour, and/or intellectual ability compared to males in order to receive an ASD diagnosis” (Duvekot et al., 2016; Dworzynski et al., 2021; Ratt e al. 2018; Russell et al., 2011; cited by Tsirgiotis, et al., 2021). Such barriers to diagnosis are concerning, as further research in this field indicates that young autistic women are doubly likely to develop depression relative to their neurotypical peers and 11.9 times more likely to ultimately require medical care in psychiatric hospitals (Eaton, 2018, p. 166; p. 15). In memoirs, essay compilations, and personal testimonies by autistic women, there is an overwhelming theme of “relief” upon diagnosis, alongside an eventual dissolution of self-doubt and self-blame, guilt, and uncertainty around their differences from others (Honeybourne, 2016, pp. 73-80). Thus, the need for research into autistic women’s experiences is a necessary step in the movement to decrease stigma, promote effective diagnostic tools, and determine necessary interventions for autistic women experiencing mental health challenges. This project aligns with the growing efforts in academia to engage in equitable studies. The aim of this study is to add research to the topic of female autism that’s based on personal narratives in order to humanize and destigmatize autistic people and their perspectives. By centring autistic women’s unique experiences, the goal of this project is to challenge the longstanding tradition in research on autism of excluding autistic perspectives and autonomy (Pellicano, Houting; 2022; p. 385).

## II. Study Design

The research question guiding this study was the following:

How do late diagnosed autistic women recount their experiences of the period immediately following their diagnosis?

To address this question, I began with an extensive literature review, starting with academic articles covering the symptoms and presentation of autism in women as well as the barriers faced by adult women seeking diagnosis. In conjunction with the text *Girls and Autism: Educational, Family and Personal Perspectives* (Carpenter et al., 2019), these papers led me to identify common concepts addressed in academic writing focused on autistic women. These common concepts are listed in Figure 1.0. I then read memoirs and essay compilations written by autistic women, noting on a spreadsheet each page in which of one of these concepts was mentioned, either implicitly or explicitly. This gave me insight into where academic research and personal narratives from autistic women about their experiences overlap. The concepts with the most frequent mentions became the focus of my interview guide. I interviewed 5 autistic women who had been diagnosed after the age of 15. These women were initially contacted on my behalf by Trinity College Dublin's Disability Service. The Disability Service agreed to share a brief letter from me, alongside an information leaflet and consent form. Recipients could then self-select to participate in interviews. Interested candidates were instructed to email me directly, at which point we discussed any questions or concerns they had and preceded to schedule an interview, whether in person, on Trinity's campus, or via Zoom. Interviews ranged from 35 to 60 minutes in duration, including reviewing the consent form and answering any remaining questions participants had. I chose semi-structured interviews in order to provide enough flexibility for participants to share their unique experiences. I prioritized open-ended questions so that participants felt able to emphasise the aspects of their experiences that felt the most authentic. I probed and prompted participants when in search of clarification or specificity. Participants were informed that they could choose to skip any of the questions and provide answers in whatever format felt the most comfortable. They were also able to request a copy of their transcript in order to strike, amend, or add statements as they saw fit. Each interview was recorded and uploaded in an MP4 format for automatic transcription by the service HappyScribe, a program which aligns with GDPR standards. Participants' personal information was protected via a series of codes

for identifying each recording and transcript. The answers to each question were compiled in a spreadsheet, at which point I conducted a thematic analysis, in line with Virginia Braun and Victoria Clarke's *Thematic Analysis: A Practical Guide* (2022). The resulting themes and subthemes are presented in Figure 2.0 and discussed in depth in the analysis section of this report. Participants were offered the option to opt out of sharing direct quotes from their statements in this report.

### **III. Philosophical Note**

The interview guide for this study was developed with a phenomenological, inductive approach. My primary source for determining my study's approach was the third edition of Svend Brinkmann and Steinar Kvale's *Interviews: Learning the Craft of Qualitative Research Interviewing* (2015). I chose the qualitative research method of semi-structured interviews based on the recommendations of Bernard, et al. in their 2023 paper "Not Your 'Typical' Research: Inclusion Ethics in Neurodiversity Scholarship." They emphasised the importance of allowing for open responses when seeking to gain insight into the experiences of neurodiverse individuals so as not to embed one's own perspective and skew the questions (pp. 52-53). It is important to note the potential drawbacks of semi-structured interviews, including the persistent debate surrounding objectivity in qualitative research studies. For this project, I have attempted to follow Brinkmann and Kvale's advice in "striving for objectivity about [my own] subjectivity," by reflecting during each phase of my project on when and how my own preconceptions have influenced my approach (2015, p. 278). Lastly, in my development of interview skills I also engaged with Eric Drever's book *Using Semi-Structured Interviews in Small-Scale Research: A Teacher's Guide* (1995). Upon request, I can provide a longer list of all of the academic papers I consulted as I prepared my study design.

### **IV. Sample**

As previously mentioned, I interviewed five autistic women who had been diagnosed after the age of 15. These women were all engaged with higher education at various levels, pursuing Bachelors, Masters, and Doctoral degrees in their chosen fields. Participants preferred not to

use person-first language (person with autism) and instead chose to be referred to as autistic people. None of the participants expressed their answers non-verbally, though the option to answer the questions in any comfortable way was offered at the start of each interview.

## **V. Interview Questions**

*Questions in bold were prioritized, those not in bold were asked, time permitting.*

- 1. Can you tell me a little bit about yourself? (Job, interests, hobbies)**
- 2. When were you diagnosed? (How long ago + self diagnosed/professionally)**
- 3. What was your experience of the diagnostic process?**
  - a. If not answered: How long did it take from your first (professional) inquiry to final diagnosis?*
- 4. How would you describe your personal reaction to receiving an autism diagnosis?**
  - a. Some autistic women refer to their diagnosis as a 'relief.' How do you feel about this? Does this align with your experience?*
- 5. Did you have anyone close in your life that was aware of your diagnosis at the time?**
  - b. How would you describe their reaction to your diagnosis?*
- 6. Were you referred to other resources or supports by your diagnostician/doctor/psychiatrist?**
  - a. Did you avail of these support services?*
  - b. Which resources did you find the most helpful? Which resources, in your opinion, needed the most improvement, and why?*
- 7. Outside of these resources (if applicable) What did you find the most helpful in the months following your diagnosis?**
- 8. How would you describe your experience as an autistic woman before diagnosis?**
- 9. What effect, if any, has diagnosis had on your life?**
- 10. How do you experience the intersecting identities of being a woman and being autistic?**
- 11. If you had to offer advice to a late-diagnosed autistic woman, what would that be?**
- 12. Along the same line, if you had to offer advice to professionals responsible for diagnosing adult women with autism, what would that be?**

13. In your own words, how would you describe what it means to be autistic?

14. When do you feel the most empowered?

**15. Is there anything else you'd like to add? Anything else we haven't discussed that you'd like to mention?**

## VI. Data Analysis, Coding

Figure 1.0 Concepts identified in academic literature and tracked in writing by autistic women

Concept	Description
Understand	Writer mentions newfound understanding of their previous experiences or feeling understood by others post-diagnosis
Belonging/Community	Writer mentions connections with autistic community or finding community supports
Explain/Answers	Writer describes their diagnosis leading to 'answers' about previous challenges or explaining earlier experiences
Alone/Isolated/Not like others	Writer expresses the difference in themselves from others, compares themselves to neurotypical individuals
Resources	Writer mentions professional or medical resources used post-autism diagnosis
Accident/Luck	Writer's diagnosis was unexpected or arose as a coincidence
Family Response/Relationship	Writer mentions familial concerns or reactions, or expresses care regarding family's well-being
Personal Research	Writer mentions personal research conducted to understand autism diagnosis or self-identify as autistic
Confusion/Surprise	Writer claims to have been confused or surprised about their diagnosis
Identifying with diagnosis	Writer either self-identifies or refers to themselves as part of the autistic community, or shares experiences in terms of autism
Resolve	Writer mentions relief or resolve upon receiving diagnosis or implementing strategies thereafter
Change in self	Writer discusses or mentions changes in their personal lives or self following diagnosis
Misconceptions	Writer critiques misconceptions or mentions misconceptions' influence on their late diagnosis

Figure 2.0: Themes and Subthemes

THEMES	SUB-THEMES	EXAMPLE QUOTATIONS
<b>Comparison</b>	Imposter Syndrome  Self-Doubt  Benefits of autistic community	<i>"The more I read about it and the people that were experiencing and stuff like that, the more it was actually like that- my experience and even stuff that I thought was normal or that was the way everyone experiences things - Um it wasn't. It was particular to this."</i>
<b>"Crash and Burn"</b>	"Flying under the radar"  Vast life changes  Other mental health challenges	<i>[referring to brother's diagnosis] "So he is one of those more typical cases of the young boy who isn't doing well in school...I - it just, kind of, flew under the radar or whatever"</i>  <i>"Like, if I could just live with it, then it's fine. But then I s-like I wasn't able to live with it anymore"</i>
<b>Communication</b>	Boundaries and Emotional Expression  Humanistic, or neurodivergent, approach	<i>"I can look out for myself so much better and...navigate the world with a bit more confidence and self assurance...I feel like I have this whole like lexicon where I can accurately describe what's going on"</i>

Figure 1.0 depicts the concepts identified during an initial literature review of academic research papers. I tracked these concepts throughout a series of memoirs, essay compilations, and personal testimonies by autistic women. Many of these concepts were identified implicitly, though every attempt was made to read the texts as closely as possible. The mention of these concepts was tracked per page, meaning even if a concept was mentioned multiple times on one page, it would receive one count for that page, so as not to confuse multiple mentions of a concept and one discussion of a concept. After totalling the mentions of these concepts, the following order of frequency emerged. The concepts are written in what follows in order from most mentions to least mentions:



(1) Alone/Isolated/Not like others, (2) Identifying with diagnosis, (3) Family Response/Relationship, (4) Misconceptions, (5) Belonging/Community, (6) Change in self, (7) Confusion/Surprise, (8) Personal Research, (9) Resources, (10) Resolve, (11) Explain/Answers, (12) Understand, (13) Accident/Luck

Please note, this is a rough estimate of the frequency of these concepts, given that some works contained chapters not relevant to late-diagnosed autistic women's experiences in the period following diagnosis. Generally, the above pattern emerged, but one ought not to extrapolate this data to be used in another context without examining these texts themselves. A list of consulted texts is included in the Works Cited section of this report.

From this literature review, I developed my interview guide, included in the Interview Guide section of this report. Upon completion of the interviews, I carried out the procedure of transcript review and thematic analysis as discussed in the Study Design section. Consequently, I identified the themes and subthemes depicted in Figure 1.0. In the following section I will analyse and discuss these themes with reference to other literature on this topic.

## **VII. Analysis of Identified Themes and Sub-Themes**

### **THEME 1: Comparison**

A central theme emerging from the interviews was comparison and its potential for benefit or harm. Participants revealed a propensity to compare themselves with others, whether neurotypical individuals or autistic men, which often led to self-directed frustration and imposter syndrome, respectively. However, upon contact with the larger autistic community, which some participants experienced, they reported an improved sense of self-understanding, identity, and empathy. In this sense, the habit of comparison led to primarily negative outcomes pre-diagnosis and positive outcomes post-diagnosis when finding shared experiences and empowerment within the autistic community.

#### **(A) Imposter Syndrome**

By imposter syndrome, I am referring to participants' claiming to have questioned their identity as autistic or comparing their presentation with stereotypical and male presentations of autism in a way that leads them to doubt whether they are truly autistic. This sense of

imposter syndrome seemingly follows from the longstanding gender discrepancies in autism diagnoses as well as reported inconsistencies in the DSM-5's ability to properly identify autistic women, as discussed in the Introduction section of this report. When asked whether she had previously considered a potential autism diagnosis, one participant claimed:

"I didn't consider because it wasn't really the idea that I had about autism. I mean I kind of had the impression that it was not the sort of thing you could not, you know, ... I mean, probably a lot of people say this, but I kind of didn't think it's the sort of thing that, you know, people wouldn't notice that you had it."

This participant went on to reveal that she experienced doubt post-diagnosis, believing her diagnostician was "predisposed" to suggest an autism diagnosis or that her brother's previous autism diagnosis played a part in the alleged predisposition. Once she read *Aspergirls*, an informative book about women and girls with Asperger's and Autism by Rudy Simone, she began to identify with the diagnosis. She explained:

"The more I read about it and the people that were experiencing and stuff like that, the more it was actually, like that- my experience and even stuff that I thought was normal or that was the way everyone experiences things. Um, it wasn't. It was particular to this."

In this way, her initial doubt surrounding her diagnosis seemingly began to dissipate upon further engagement with information for autistic women. Another participant reported a similar experience, in which her internal comparison of her behaviour to her autistic brother's behaviour prevented her from considering an autism diagnosis earlier on. In a consultation with a mental health counsellor, she described the following exchange:

"And presented her with a list, like, I suppose, of traits and things that bother me day to day. Um, and then she was kind of like, 'Yeah, maybe ADHD, but sounds more like'...um... I think she referred to it as ASD at the time. And yeah, but like, just.. something I never considered, I suppose, in part because I'm so different to my brother [okay] that I'm like, 'Well, I'm not like him.' Therefore, you know, we're not the same. I think it was maybe partly where my logic was coming from with that, yeah."

One of the most explicit accounts of this imposter syndrome came from a participant who had been receiving accommodations similar to those offered to autistic students throughout primary school and pursued a diagnosis as an adult. Despite feeling aware of autism as a possibility, her account of the diagnostic process suggests that receiving the label of autism served as confirmation of her experiences:

“Throughout the whole process, I was like, “Am I thinking it?” I know I technically had a diagnosis and I didn’t know about it, but I think it was still a bit reassuring to me.”

These accounts, in conjunction with another interviewee’s emphasis on the difference between her autism presentation and the presentation of a young autistic boy she cared for, reveal the pervasiveness of overrepresentation of men’s autistic experiences in fuelling autistic women’s doubt or disbelief in their diagnosis.

#### (B) Self-Doubt

The subtheme of self-doubt represents another form of comparison participants engaged in: comparing themselves with neurotypical individuals. Though the autistic experience is often explained in contrast to the neurotypical experience in order to promote empathy and understanding, this method might promote insecurity or self-doubt in autistic women, particularly before diagnosis. This is because neurodivergent presentation is often regarded in terms of “faults,” or individual struggles. This individualistic perspective on disability is rooted in a medical paradigm, in which the autistic experience is perceived in terms of “functional deficits,” and the strengths associated with autism are portrayed as “islets of abilities among a sea of deficits” (Pellicano & Houting, 2022, pp. 381-382). Over time, there has been a slow transition from a medical paradigm to a neurodivergent paradigm, wherein differences in cognition are accepted and seen as natural (Pellicano & Houting, 2022, p. 381). From this perspective, the challenges faced by the neurodivergent community arise from a clash between a society that caters towards the neurotypical population and the reasonable, necessary accommodations requested by the neurodivergent population (Pellicano, Houting; 2022; p. 387). Some interviewees in this study shared how their perception of their challenges shifted post-diagnosis. When asked about her personal reaction to diagnosis, one participant noted:

"But it was great, it was great actually, like I'm really... In hindsight, I'm really grateful for it. It just explains so many things that I just [yeah] kind of, um... you know, things that I just accepted, things that I just thought, "Oh, I just can't do this, or I'm just not good. It's just the way I am, or whatever."

She also shared, in reference to her autism diagnosis:

"It was just- there were parts of it that I wasn't... that were... That were causing problems for me because I was expecting myself to be able to respond to things like when you're a neurotypical person."

This interviewee's response reveals the damages of assuming and expecting neurotypicality when undiagnosed, such as concluding that one is "just not good," or not able to do certain things. After diagnosis she was able to contextualise her previous struggles and understand the harm in applying the medical paradigm rather than neurotypical paradigm to her experiences. Another participant described her experiences post-diagnosis in terms of an alleviation of guilt around previous behaviour when she had fought to conform to neurotypical norms:

"I definitely feel less guilty about a lot of things. Definitely more. Before, I could feel guilty about maybe getting so tired in such situations or in being out and about all day. Now, I don't, which is nice. I've also been able to change."

Following her diagnosis, this participant implemented strategies and a positive internal dialogue to aid in her daily life. In this way, her diagnosis might be described as a "relief" from the burden of guilt. Notably, the theme of relief arose frequently in writings by other autistic women, as well.

Though the benefits of diagnosis are apparent in relieving some of the guilt experienced by undiagnosed women, it is important to consider the long-term effects of carrying insecurity and shame from a young age. This theme is not constrained to this study. Judy Eaton describes her experiences working with autistic women in mental health settings and writes the following:

"A common theme when working with young women, particularly those who have received a late diagnosis, is low self-esteem combined with huge feelings of shame

and guilt, particularly those who have been prone to emotional outbursts” (2016, p. 179).

Furthermore, given the societal “burden” placed on women to be social and empathetic, autistic women may be left “feeling ‘defective,’” as “their strengths may not lie in those traditionally female roles” (Honeybourne, 2016, p.49). Thus, the potential, harmful aspects of the traditional, medical paradigm and the frequent late diagnoses of autistic women are apparent.

### (C) Benefits of Autistic Community

A key area of focus in the semi-structured interviews was the supports offered in the post-diagnostic period, including which supports were beneficial and which could have been improved upon. A common theme among participants was their disappointment with the offered supports. Many felt that once they had received their diagnosis, they had little to no follow-up appointments or support in accessing the recommended resources. Consequently, they were expected to seek out supports individually, with a lack of guidance from their diagnosticians. This pattern aligns with a study conducted by Vohra et al., cited in by Eaton (2018), where the researchers found that parents in the United States were “dissatisfied” and stressed in the absence of help from medical professionals following their child’s autism diagnosis (p. 159). Eaton uses the idiom of “jumping through hoops,” to describe parents’ and families’ attempts to avail of the necessary supports to aid their child (2018, p. 170). Though my study examined adult diagnoses, it is crucial to consider these difficulties, which could potentially be heightened by the expectation of adult self-reliance and the women’s simultaneous engagement in university work. When questioned about post-diagnosis supports, several participants discussed their reliance on the autistic community, given the lack of medical or professional outreach and support. The following quotation is a participant’s response to a question about what they would offer as advice to recently late-diagnosed autistic women:

“Um... definitely community and, kind of, finding your peers is a big one - which is very easy uh, because uh you, come then to discover that neurodivergent people just unconsciously are drawn to each other...”

This theme continued in a different participant's response to the same question. She advised:

"And find your people. Find your people. That's the big one."

Later in her response she expanded on this point:

"Just connecting with other neurodivergent people, other disabled people, and people who just get it, it's so much easier and it's so much nicer. There are people that you get to choose to spend your time with."

She posits that spending time in the neurodivergent community is an expression of choice that prioritizes one's well-being. In conjunction with literature on the autistic experience, finding a community of shared understanding and empathy seems highly significant in shaping the mental-health outcomes of autistic women. This is because "many girls with Asperger's report feeling misunderstood" in classroom settings (Honeybourne, 2016, p. 161). How this feeling might impact undiagnosed women has not arisen in my literature review, but the self-doubt and relief upon finding community shared by participants illustrates a similar concept. Lastly, in discussing supports, at least two of the women explicitly addressed the benefit of resources by and for autistic people. One participant claimed that:

"I know in the US, there's some organisations ran by autistic people. I think as soon as you actually start looking for information written by autistic people themselves and not others, you tend to change your perspective pretty quickly."

She used the analogy of reading literature on "women's issues" written by men to describe seeking neurotypical-organised supports to address autistic needs. This speaks to the necessity for community for women learning to process and accept their autism diagnosis. This sub-theme connects to the importance for neurodivergent-friendly language in the medical profession as well as the need for increased understanding of the post-diagnosis experience by diagnosticians.

## THEME 2: Crash and Burn

Another central theme that arose from the interviews and was also reflected in literature surrounding the mental health of autistic women is the theme of 'Crash and Burn.' By crash and burn, I am referring to the increased level of difficulties autistic women must present with, relative to autistic men, in order to be diagnosed. Three of the five participants

discussed pursuing a diagnosis following or during a noticeably challenging point in their lives, with two participants reporting dramatic decreases in their well-being prompting their diagnosis. Given that the tendency to mask autistic presentation is relatively higher among women, this theme encapsulates the heightened expectation placed on autistic women, whether self or externally imposed, to conform to neurotypical norms until it is no longer possible for them to feel autonomous or mentally healthy. This delayed period often coincides with a development of mental illness due to trauma or misdiagnosis.

#### (A) Flying Under the Radar

As addressed in the introduction section of this report, current diagnostic tools tend to exacerbate the discrepancy between women and men's autism diagnostic rates. The insufficiency of these tools is heightened with the addition of autistic women's masking. A woman's personal testimony in Victoria Honeybourne's book *Educating and Support Girls with Asperger's and Autism* reveals her life pre-diagnosis and she states that, "[she] was doing a lot of pretending," because she couldn't explain her differences to peers (2016, p. 73). This is echoed in *Ultraviolet Voices: Stories of Women on the Autism Spectrum*, a compilation of essays by autistic women edited by Dr. Elizabeth Hurley. In her essay in this compilation, Cynthia Kim aptly uses the phrase "hide in plain sight," to describe her heavy use of masking to hide her presentation of autism as a young girl (2014, p. 31). There is an increasing obligation for medical professionals to understand the role of masking in autistic girls and women so that they may receive diagnoses and appropriate supports as soon as possible.

In this study's interviews, the concept of masking was mentioned by some of the participants, but many of their explanations for not receiving a diagnosis earlier in life are linked to their self-comparison to men's typical presentation of autism. Though discussed in the first theme of "comparison," this phenomenon is important to consider when seeking to understand why women tend to be diagnosed relatively later than men. One participant, after explaining the difference between her autism presentation and that of a young boy she was caring for said:

"... I was gonna- I've always been extremely verbal... So, you know I think that kind of helped- had me kind of fly under the radar for so long. [yeah] Yeah."

The same participant discussed her history with masking as a potential factor for her late diagnosis, stating:

“So, um I like- I would say that like theatre taught me how to be a person... But I can like- I can remember being... I think my first memory of like consciously choosing to mask was around three or four years old.”

In other instances, a lack of earlier diagnosis might be linked to an absence of other intellectual disabilities. One participant expresses her parents’ reaction to her challenges as follows:

“Um- And so like kind of my parents, my parents are the best, but they didn't really, like... They were not really ready to accept that I was struggling in different ways. Um, so they were like, 'Well, you can read. You read loads of books and your grades are really good, so you're fine.'”

In this way, potentially influenced by misconceptions surrounding neurodiversity and autism, her parents disregarded her expressed struggles based on her academic performance. This example reveals the effects of misconceptions and a lack of representation of autistic women on parents’ and caregivers’ abilities to understand and account for their child’s difficulties. Victoria Mason addresses the issue of representation for autistic women in her *Ultraviolet Voices* essay, as well (2014, p. 20). She writes “I didn’t see myself reflected back in anybody else (real or in the media). I felt that there must be something wrong with me” (Mason, ed. Hurley, 2014; p. 20). Though, as Cynthia Kim writes, “stereotypes carry with them the burden of proving them wrong,” the lack of accurate, considerate representation for autistic women in the media is troubling and seems to feed into the history of autistic women “flying under the radar” (Kim, ed. Hurley, 2014, p.24).

## (B) Vast Life Changes

Notably, this is a smaller sub-theme, with less discussion in the literature on this topic. However, three of the five participants reported vast-life changes prompting their pursuit of a diagnosis, and one other participant explained that her use of mental health resources prompted her diagnostic process. One participant specifically mentioned that her other



chronic health conditions revealed to her that she might receive an autism diagnosis, but her experiences during the COVID-19 pandemic afforded her time to reflect and decide to see an autism diagnostician. Two participants disclosed that their autism diagnoses resulted from mental health and functioning difficulties that grew to an extreme extent. One woman shared that her experience moving from home into university abroad revealed her challenges with autism:

“I'd gone away to college in England. I'd done two years, and I think that kind of like, um... I, I kind of ... I Struggled a lot with issues at the time I didn't realise that they are kind of related [okay] to the diagnosis... the diagnosis, but um... Just time management, organisation, emotional regulation, that kind of stuff. Um, uh, so yeah that was- I withdrew after two years of that programme, which was one of the triggers of the diagnosis.”

Similarly, another participant stated the drastic decrease in her well-being, when she initially believed she had obsessive compulsive disorder, drove her to pursue a diagnosis:

“Like, if I could just live with it, then it's fine.' But then I s- like I wasn't able to live with it anymore. I was having like really lik-like issues that I wasn't able to kind of live with.”

For these women to receive an autism diagnosis, they had to be faced with extreme challenges in life, whether feeling unable to function at university, confronting solitude in COVID-19, or feeling as though they couldn't cope anymore. Because of the widespread misunderstanding of women's presentation of autism, these women had to experience intense struggles in their personal lives to receive a diagnosis that would enable them to access appropriate supports. The pattern of young women requiring intervention before receiving a proper diagnosis ought to be concerning for teachers, medical professionals, and families. With the increase in knowledge about mental health conditions experienced by autistic women and their heightened tendency to mask, the trajectory for late-diagnosed autistic women is unhealthy and unjust.

### (C) Other Mental Health Challenges

Another sub-theme discussed frequently by interviewees, as well as in academic literature on autistic women, was the mental illnesses they cope with. All participants in this study either suspected or had a mental illness at the time of diagnosis or had been receiving

professional support, whether occupational therapy or general counselling. Reported mental illnesses or suspected illnesses were anxiety symptoms, general anxiety, depression, and obsessive compulsive disorder. While I cannot speculate as to the source of these illnesses and symptoms, Eaton's (2018) reported figures on the disproportionate representation of mental illness among autistic women suggest a larger pattern that ought to be analysed further. As part of my analysis, I would like to include more research on the mental health struggles faced by autistic women and re-emphasise the importance of early diagnosis and intervention. In an "informal audit" of the Child and Adolescent Mental Health Services inpatient unit she worked in, Judy Eaton found that approximately 36% of the young girls receiving treatment met the criteria for an autism spectrum diagnosis, with many girls having been misdiagnosed with Borderline Personality or Schizo-affective disorder (2014, p. 14). Eaton also discusses the prevalence of eating disorders in autistic women as a form of control to "[manage] their anxiety and [tolerate] uncertainty in other areas of their lives" (2014, p. 147). With this, "over 80% of autistic women" (labelled as women with Asperger's or high functioning autism in the cited text) "considered themselves to experience anxiety, worry or stress frequently" in a survey (Baldwin & Costley, 2015; cited in Honeybourne, 2016, p. 59). Ultimately, the prevalence of mental illness in autistic women is necessary to understand when urging medical professionals to gain and spread awareness about the differing presentation of autism in women.

### THEME 3: Communication

The final core theme identified is the importance of communication to autistic women in the period immediately following their autism diagnosis. Interviewees typically agreed that their diagnosis was a relief, and many reported an increase in self-awareness and empowerment following diagnosis. The first two subthemes refer to the changes the women experienced in their ability to communicate their needs or emotions and implement tactics such as boundaries to improve their overall well-being and decrease their feelings of self-doubt or guilt. Another important aspect of communication addressed within this theme relates to the way autism is discussed by medical professionals and society at large. When asked to describe what being autistic means to them, participants emphasised the necessity to regard autism as not inherently negative and sometimes positive but rather to view autism through the neurodivergent paradigm, which will be discussed in the following sub-section C.

## (A) Boundaries and Emotional Expression

When discussing their personal reaction to receiving an autism diagnosis, participants tended to focus on their emotional reaction and the changes they implemented in their lives, informed by either their own personal research or advice from their diagnostician. Two key concepts that arose in interviews were increased confidence in setting boundaries to protect well-being and improved emotional literacy. One interviewee claimed her self-assurance increased following her diagnosis, which heightened her self-understanding. She said:

“I can look out for myself so much better [sure] and therefore just, kind of, navigate the world with a bit more confidence and self-assurance, I think... Um... and also just being able to be much more candid and open with people, which is not something I was actively avoiding doing. It was just like I said, I felt I didn't have the communication to do that. Um... whereas like now I feel like I have this whole like lexicon where I can actually accurately describe what's going on, um... And just, yeah, just being able to kind of talk through my feelings...”

For this participant, an autism diagnosis prompted her to prioritize her well-being and develop an improved sense of her emotions. Receiving a diagnosis initiated her growth, and as emphasised in the above quote, has aided her ability to communicate openly and confidently with others. This points to an increased sense of empowerment post-diagnosis, and interviewees often expressed their gratitude for receiving a diagnosis and thus the opportunity to understand and support themselves. Improved confidence following diagnosis is mentioned frequently in literature by autistic women, and in a personal testimony from Honeybourne's book, one autistic woman urges young autistic women to “find out who they are before it is too late” (2016, p. 65). Access to a diagnosis and consequent resources can spark a journey of self-discovery for autistic women and lead to invaluable opportunities to improve their well-being. Another sign of this improvement is the setting and maintaining of boundaries by autistic women to prevent burnout, undue anxiety, and overstimulation. Referencing the anxiety she often has after work, one participant stated:

“I want to have boundaries. This is the time that I'm paid to work, and then this is the time that I get to go home and relax. I don't need to think about it and unpack every interaction that I have with everybody in the office today.”

These quotes indicate the benefits of an autism diagnosis for women in allowing for heightened self-awareness and implementation of adaptive strategies to face environments organised with neurotypical individuals in mind.

#### (B) Humanistic, or Neurodivergent Approach

The last subtheme that surfaced from the interviews was the positive impact that neurodivergent language has on the self-image and perception of autism for the interviewees. This subtheme is closely linked with the subtheme of the benefits of the autistic community, in that neurodivergent-friendly language from diagnosticians or counsellors seemingly promotes a more positive outlook on women's autism diagnosis. One participant shared the following about the need for neurodivergent-friendly language by diagnosticians:

"I think so. I went to someone who specialised in adult assessment specifically and who had a very positive attitude about being autistic in general, which I think is very helpful. They tried to make the whole process as accommodating as possible." ...

"Then even throughout that, still framing it as not a disease diagnosis, but more of like, "This is just patterns in your behaviour, and we name it in this way, which was nice."

This account contrasts with a medical paradigm-influenced view on autism, where diagnosis is expected to "prompt grief and mourning" (Pellicano, Houting; 2022; p. 383). The characterization of autism as inherently negative, socially maladaptive, or due to individual failure contributes to stigma, dehumanization, and loss of dignity for autistic people. One interviewee summarized potential insecurities resulting from this classification of autism, positing:

"... like anyone who uses more medical or pathological language to describe it can be... There's no way to really hear that and feel good about yourself afterwards."

As discussed, gaining an autism diagnosis has the potential to ignite a period of self-discovery and self-compassion. The rewards and joys arising from this period ought not to be overshadowed by diagnosticians or counsellors relying on an outdated conception of autism which serves to discriminate against and garner insecurity within autistic women and the autistic community at large. Jim Sinclair's essay "Don't Mourn for Us," addressed to parents

who have learned their child is autistic, is a profound testimony to the need for a change in how society perceives and discusses autism. Sinclair acknowledges the grief parents might experience when considering the differences in their child's and their family's lives, while encouraging parents to advocate for, support, and understand the extensive efforts of their child (Sinclair, 1993). Though Sinclair specifically writes to parents, his arguments apply to the tradition of widespread, misplaced sympathy for neurodivergent individuals, a by-product of the medical paradigm's influence. Rather than continue to draw harmful comparisons between neurotypical and neurodiverse women, the strength, skill, persistence, and courage of autistic women ought to be celebrated, while progress continues towards a more equitable, diverse, and disability accommodating society.

## **VIII. Conclusion and Recommendations**

The three central themes identified in this study reveal the core components of the interviewees' experiences leading up to and following their autism diagnosis. Firstly, across the interviews, participants shared, whether explicitly or implicitly, their tendency to compare their presentation of autism to others, in particular, men. This tendency was reflected in some women having not previously considered a potential autism diagnosis as well as having misconceptions about autism that led them to question the extent to which they aligned with the autistic community. Further research and reflection shifted several participants' perspectives, in that they began to lessen their sense of self-blame for the challenges they faced, putting their struggles in the context of an identifiable diagnosis. Contact with the autistic community was overwhelmingly recommended as a helpful support in the period following diagnosis. The 'crash and burn' theme and associated sub-themes refer to the women's lack of diagnoses, until prompted by vast life changes such as COVID-19 restrictions or leaving for university. Many women felt as though their diagnosis was hidden for a period due to a differing presentation of autism relative to male counterparts, resulting in a belief that they had a mental illness such as anxiety or depression. Lastly, the theme of communication refers to the growth some participants reported experiencing following diagnosis, as the 'label' of autism allowed them to explore improved support tactics and feel more empowered and able to communicate their feelings and needs. This theme linked

closely with the emphasised importance in interviews on discussing autism from a humanistic viewpoint, as opposed to a pathological one, wherein autism is an individual 'problem,' or something inherently negative. With these themes in mind, the emerging data from the interviews indicate a need for increased contact with the autistic community for late-diagnosed autistic women, an improved understanding of women's presentation of autism societally, as well as a more considerate dialogue surrounding autism on a larger scale.

Lastly, I would like to address further questions and potential research avenues, whether philosophical or sociological, that I am interested in exploring in the future. Both in interviews and the personal memoirs, a common theme arose: defining the autistic (and neurodiverse) experience relative to the non-autistic (neurotypical) experience. This theme is best explained in the context of Simone de Beauvoir's argument in her book, *The Second Sex*. De Beauvoir claims that women's identities and the concept of femininity have been contextualized in relation to men's identities, in a way that prioritizes masculinity as the "default." As a result, the feminine identity is characterised as a negation of masculine identity and as such, rather than frame women's experiences in a unique way, society continuously depicts womanhood as a lack of that which is masculine, thereby devaluing women and belittling their opportunities to self-actualize authentically. Though de Beauvoir is writing with gender in mind, her theory relates to much of the literature I have read surrounding autism. Even in texts that seek to empower autistic people, there remain constant comparisons to the neurotypical experience. Accordingly, what's defined as the autistic experience is largely a distinction from the neurotypical experience. While in some cases, explaining the differences in neurotypical and neurodiverse frameworks can promote empathy and shared understanding, in literature by and for autistic people, I believe that an overemphasis on these differences is a disservice to the autistic community at large. I attempted to avoid leaning into this dichotomy in my interviews, by questioning participants about their personal experiences and specifically asking, 'What does it mean to be autistic?' My goal in asking this question was to gain insight into how the autistic identity might be explicated, outside the bounds of a neurotypical context, in which a lack of neurodiversity is considered "default." Interestingly, participants still largely reported their perception of autism as a type of "difference," which, though understandable, points to an internalised bias with roots in the dominant neurotypical perspective. Notably, I recognise there is a fine line between garnering a group identity and

failing to recognize the diversity of experience within a group. Even still, to truly respect the autonomy and dignity of a historically marginalised group, in my opinion, requires acknowledging that group's lived experiences independently from the confines of majority assumptions and expectations. Thus, after reflecting on my project, I would like to pursue further inquiry into the process by which groups are categorized, understood, and, as a result, treated, both from the perspective of those within the community and the views of those outside of it. Essentially, my research has ignited my newfound passion for deconstructing the role of internal and external understandings of identity. I hope to explore this theme in later projects and analyses of autistic literature. Another component of my research that I would like to improve on in future projects and associated work is inclusivity. My project focused on the experiences of late-diagnosed autistic women, and I worked with Trinity's Disability Service to source participants. I struggled to establish connections with other organizations to contact participants and admit that my sample group represents a small portion of autistic women. Specifically, my group consisted of verbal autistic women with the privilege to pursue higher education. Thus, these results ought not to be over-generalised given the immense diversity of autistic experiences. Moving forward, I would like to work with a wider range of autistic women from different socio-economic groups and backgrounds. Similarly, I would like to include the perspectives of gender minorities in future projects, which was also recommended to me by a respondent. By examining the role of identity and prioritizing inclusivity, I believe I can engage with increasingly nuanced research and outreach in the future.

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Citations for academic journal articles consulted in my initial literature available upon request.