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Research

A phenomenological exploration of the occupational identity of late-diagnosed autistic women in the United Kingdom

Jessica Lynch¹  · Angela Murphy¹  · Daniel Cezar Da Cruz¹ 

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Abstract

Many autistic women without an intellectual disability receive their diagnoses later in life. Little is understood about how gender, autism, and a late diagnosis intersect to impact the occupational identity of these individuals. Purpose: the current study aimed to explore how autistic women who received a diagnosis in adulthood describe key areas that influence the development of occupational identity. Methods: eight participants recruited from social media were interviewed through semi-structured interviews, and a reflexive thematic analysis was conducted on the rich accounts of their lived experiences. Results: three major overlapping themes included experiencing disconnection from one's own volition, striving for occupational balance, and acceptance as a protective factor within these women's lives. Subthemes were in relation to personal reconciliation around difference and the dynamic between the person, environment, and the dominant socio-cultural context. The political, social, and economic landscape perpetuating neoliberal, individualistic and ableist ideals within practice is criticised considering the lived experiences presented in the findings. Conclusion: the necessity for collective health promotion through improving the basic standard of living according to the social determinants of health is highlighted.

Keywords Autism · Late-diagnosis · Women · Occupational identity · Society

1 Introduction

The social model of disability [60] holds autism to be an invisible disability: a constellation of neurodevelopmental differences (neurodiversity) that are not visible from the outside yet can limit or challenge a person's occupations due to systemic barriers, harmful attitudes, and social exclusion [87]. Thus, these differences within certain contexts can limit an individual's ability to achieve their valued functioning's within society. This lens moves away from the longstanding medicalised view of autism as a cluster of neurobiological deficits which can perpetuate a stigma of the autistic individual as defective, rather than different, with a need to change to fit into society [56]. This has sometimes led to the pathologizing of all autistic behaviours that are away from the neuro-typical 'norm' along with the promotion of paternalistic and potentially harmful treatments [42] that seek to minimise perceived deficits through behavioural conditioning and

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✉ Daniel Cezar Da Cruz, D.M.Cezar-Da-Cruz@leedsbeckett.ac.uk; Jessica Lynch, jesslynchh992@gmail.com; Angela Murphy, a.m.murphy@leedsbeckett.ac.uk | ¹School of Health, Department of Rehabilitation and Health Professions, Leeds Beckett University, Calverley Building, CL 606, City Campus, Leeds, West Yorkshire LS1 3HE, UK.



medications. This includes dedicated training to reduce stimming behaviours and teaching social skills to satisfy neuro-normative standards (forcing eye-contact, for example) [53].

Autism is characterised mainly by differences in social communication and interaction skills and unique expressions of focused and immersive interests or behaviours relative to non-autistic individuals [1]. Further, 69% to 95% of autistic children are estimated to experience sensory differences [51] which is purported to produce challenges with accessing a diversity of occupations [82]. The neurodiversity movement is a paradigm that began to spread the view of neurodiversity as human diversity [73], and as such, suggests that it is subject to the same social dynamics as other forms of diversity (including dynamics of power and oppression). The “double empathy problem,” proposed by Milton [55], contends that autistic people struggle to integrate into a society with a non-autistic majority not just because they have difficulty reading the emotions of non-autistic others, but also because they themselves tend to be misread by the non-autistic majority [56]. This is suggested to be due to neurological differences in language use and comprehension between the neuro-types [55, 56]. Experimental studies have demonstrated that the emotions of autistic participants are of similar difficulty for non-autistic participants to read which appears to often result in unfavourable first impressions of autistic people for non-autistic people [22, 72]. This suggests that a mismatch of perspectives occurs and that dominant theories that claim autistic people lack empathy are partial explanations at best. The current research does not wish to reduce the lived experience of autistic people to a single social dimension and ignore the neurobiological and mental realities of the individual, however, as a neurodevelopmental pattern, the role of socio-cultural environments on the development of the individual must be considered in relation to how an autistic individual experiences disability.

1.1 Late and gendered diagnosis: occupational identity

Current research indicates that a long-standing masculinised construction of understanding of autistic people has led to an increasing number of autistic women without an intellectual disability receiving their diagnosis in adulthood, having been misdiagnosed or missed entirely throughout childhood [39, 48]. Gendered descriptors of autistic people that were developed and normed from observing the behavioural presentation of autistic boys appear to contribute to women’s later or missed diagnosis [48, 65]; and therefore, has historically neglected the autistic female experience [58]. The androcentric focus has resulted in diagnostic practices and the development of observational assessment tools that do not measure the seemingly more internalised traits more common in females [31, 75]. Further, there is a reported unfamiliarity among healthcare professionals, teachers, and parents about how autistic girls present [80]. The under-recognition emphasises the need for the voices of autistic women to be included in research rather than relying on behavioural observations and interpretations.

Quality of life studies have highlighted that occupational therapy is uniquely positioned to facilitate more adequate assessment and intervention in response to these individuals needs which must be recognised as complex and heterogeneous [47]. Studies consistently outline more difficulties around social relationships (more loneliness), psychological health (higher anxiety/depression), and sensory processing (sensation-sensitivity behaviours) among autistic adults, with their support needs often going unmet in educational and work settings, along with reports of social exclusion and isolation, especially among women [3, 23, 24, 47, 58, 74, 82].

Despite the level of stigma and oppression that is proposed to be associated with the diagnosis or label of autism [67], a systematic review including nine qualitative studies of autistic women highlighted that late-diagnosed autistic women tend to express regret if they missed out on receiving their diagnosis in childhood [39]. Women attributed their regret to the level of insight and self-understanding that the late diagnosis provided them, as well as the feeling that they would have coped better with dangerous situations throughout their lifetimes with the self-knowledge earlier on.

According to critical studies of autistic people, and in line with the social model of disability, autistic women are impacted by two intersecting social influences (gender and autism) that are associated with experiences of marginalisation (sexism and ableism) which are proposed to impact their sense of identity and well-being [68]. It is suggested that late-diagnosed autistic women experience further specific identity threats due to not fitting the societal representations of either intersecting identity [38, 57, 80]. The fast-accumulating research on this phenomenon sheds light on the systemic disadvantages being experienced by autistic women in most areas of their lives including social exclusion, personal struggles and identity issues, and little access to appropriate healthcare or support [54].

The concept of occupational identity within Occupational Science holds that a person’s identity develops cumulatively through their engagement in occupations which provides them with a composite sense of who they are and who they wish to become as an occupational being [14, 41]. The concept is closely linked to Wilcock’s [84] proposed Occupational Perspective of Health which highlights the centrality of occupation in the health, well-being, and the self-realisation of

the individual. The Occupational Perspective of Health outlines how processes of *doing* (performance), *being* (authentic engagement), *becoming* (potential), and *belonging* (connection and interaction with the environment) powerfully guide the trajectory of one's life to inform identity. Phelan and Kinsella [62] advanced the conceptualisation of occupational identity by outlining a dialectically oriented understanding of how social and cultural dimensions (*belonging*) shape occupational identity, moving away from the notion that autonomy and free will are universally applicable constructs. These processes act as an important link between social factors and health and wellbeing [25] and it is understood that interventions that aim to merely affect individual change can be problematic as they obscure opportunities to address health and wellbeing concerns produced from occupational inequities within society [37].

The 'Female Autism Phenotype' is a proposed manifestation of autistic strengths and difficulties more common among those assigned female at birth that is becoming more apparent within research [52]. This manifestation has been suggested to be influenced by a greater social motivation and capacity for friendships among this group than that which is typically observed in autistic boys and men [26, 36]. This is suggested as a reason that autistic people also display a greater propensity for camouflaging behaviours [20] which involve employing strategies to hide their autistic traits (masking) or the use of explicit techniques that mimic neuro-normative social competence (compensating) [35]. Developmental and clinical outcomes such as the acquisition of camouflaging behaviours and co-occurring mental health difficulties are common among late-diagnosed autistic women [39]. These women have indicated a protective element to camouflaging as strategies are often used as a conscious or unconscious effort to appear non-autistic in social situations, to improve employment opportunities or social connections, and to avoid verbal and emotional abuse [5, 70]. However, camouflaging has also been associated with being routinely dismissed or misdiagnosed when seeking professional support [52, 80]. Research demonstrates that women self-report more autistic traits than professionals may observe, and the discrepancy is not as large in relation to the self-reports of autistic men [44]. Predictive characteristics for lower quality of life among already disadvantaged autistic communities included being female, scoring higher on self-reported autistic traits, and having a mental health condition [50].

Experiences of camouflaging are related to higher rates of anxiety and depression [10] and have been suggested to impact negatively on a person's sense of self [79]. Further, camouflaging has strong links to exhaustion due to the cognitive effort involved, often leading to autistic burnout which has detrimental consequences on a person's mental and physical health and capacity for independent living [66, 79]. Cassidy et al. [13] found that among those who died by suicide between 2014 and 2017 in two regions within the UK, autistic traits, diagnosed or undiagnosed, were shown to be an elevated risk factor for suicidality. Further, research has suggested that autistic women are 13 times more likely to die by suicide than non-autistic women [32] and that camouflaging is a risk marker for suicidality that is unique to autistic people [6, 86]. The current research was conducted with an understanding that the current construction of autism is a male-centric conceptualisation and supports a re-examination of its ontological status to explore the gap concerning diverse experiences across the gender spectrum. The proposed research aims to better identify the interaction between the person and the larger socio-cultural systems that influence their occupational lives and narratives by bringing an occupational identity lens to their lived experience. The research aimed to explore the phenomenon through qualitative interviews with autistic women who received a diagnosis in adulthood with a focus on both internal (psychological) and external (environmental) factors that influence occupational identity development, and in doing so, identify the barriers and facilitators to their engagement within meaningful occupations. Therefore, the research question is: How do late-diagnosed autistic women perceive their occupational identity across their lifespan?

2 Methodology

2.1 Research design

The current study draws upon occupational identity theory, critical autism studies, and the social model of disability as guiding frameworks that influenced the topic choice and aims, method and design, and concluding study discussion. However, with the double empathy problem in mind [55], suggesting that non-autistic individuals often misinterpret the behaviour of autistic individuals, care was taken to maintain the authenticity of the data. Data was first synthesized and presented in a descriptive summary before the researcher (first author) responded interpretively to the findings in the discussion. The phenomenological approach to the data was developed to help clarify how objects (concepts, constructs, life) are experienced and present themselves to human consciousness [77]. The presentation of findings is with a view

to providing as much of the participant's own voices within research as possible and then move beyond 'knowledge for its own sake' (p. 129) to using knowledge for change and power [61] within the discussion.

Moreover, our research is under the naturalistic paradigm of valuing and illuminating people's voices regarding their lived experiences rather than a positivistic paradigm where measuring and quantifying minimises the unique human experience [63]. Considering this naturalistic paradigm, critical autism studies and the social model of disability add a critical perspective to the understanding of the occupational identity phenomenon. It also challenges the status quo and provides a space for reflection and social transformation in ways of thinking, being and doing.

2.2 Participant recruitment

Eight autistic women participated in the study, recruited through purposive sampling. A recruitment poster was designed and posted on social media via a gatekeeper within a British organisation supporting autistic girls and women. The research poster invited participants to share their lived experiences regarding late-diagnosis and the way their identity was informed by the way they do things.

The inclusion criteria focused on autistic women without an intellectual disability who received a formal diagnosis of autism over the age of 18. Research indicates that a late diagnosis of autism is more common among individuals without a co-occurring intellectual disability and those designated female sex at birth [52]. This was reflected in the participant demographics collected where no gender identity history or co-occurring intellectual disabilities were reported.

2.3 Semi-structured interviews

As part of public involvement and good research practice, prior to carrying out the in-depth interviews, the principal researcher consulted an autistic consultant within a British charity for autistic people for advice regarding questions and research design. They found the research project met the recommended requirements by following: (1) ethical guidelines set out by Cascio et al. [12]; (2) use of identity first language [83], and (3) considering the literature on the use of Applied Behavioural Analysis and other such approaches based on eradicating perceived 'deficits' [53] (See Appendix 1). In-depth, exploratory interviews (see Appendix 2) were employed in May–July 2022 to gain valuable insight into (1) the internal and external mechanisms related to current phenomena and (2) how participants experience occupational identity development. Importantly, it was recognised that occupational identity encompasses complex connections comprising both individual and collective components that are interconnected, temporal, meaningful, and contextual [29]. As it was unlikely that participants would be familiar with the concept of occupational identity [15], the interview design had an inherent occupational lens, but leading questions were avoided as much as possible to protect the validity and reliability of the study, remaining exploratory.

The design acknowledges that occupational identity is made up of complex interconnections between the dimensions of occupation and that the connections exist over time; connection to previous *being*, *doing* and *belonging* inform that of the present and influence one's sense of future *becoming* [29].

2.4 Data collection

Participants responded by emailing the first researcher to express interest or ask questions. Initial contact via email and transparency (to clarify the research aims) facilitated rapport building, which has been shown to be effective for the video-conferencing style data collection which was employed [71]. Interviews took place over MS Teams with the first author, who had previous experience with autistic individuals, and the interview was recorded within the application. The interview was transcribed verbatim, anonymised, and stored for later analysis. Following the interview, a document signposting autistic support services was emailed to participants.

This study, as far as the researcher is aware, is the first of its kind to explore phenomena related to the occupational identity of late-diagnosed autistic women, and so eight participants were thought to be a sufficient basis for future research on this matter, given the limited timeframe during a master's programme as unfunded research. However, it should be noted that 4 other potential participants expressed interest in the study. Of these, two presented with inconsistent communication and missed the deadline to take part, one did not respond after initial contact, and one was an individual residing in the United States who made contact after the deadline. A selection bias may exist for those that are able to consent and convey their life experiences orally which may need to be addressed in future research.

Demographic information was collected orally at interview to consider the heterogeneity within the sample (Table 1). Details of the participant's ethnicity, spiritual beliefs, or nationality were not recorded; however, all participants presented as white British. The average age at diagnosis was 41.75. All eight participants who were interviewed were included in the final analysis and were assigned a pseudonym to ensure anonymity.

2.5 Data analysis

Reflexive Thematic Analysis was inductive and according to the six phases of Braun and Clarke [9]. In Phase 1: The researcher methodically familiarised themselves with the dataset by becoming immersed in the information through transcribing the recordings and several readings of the transcription, making note of ideas. Following this, in Phase 2, the researcher carefully coded the data by marking each item and noting which ones formed interesting groups with shared meanings from participants responses. Both semantic (surface meaning) and latent (implicit meaning) codes were generated. In Phase 3, the researcher began to search for patterns in the dataset to construct themes and sub-themes, grouping the codes into related categories and noticing where overlap occurred. In Phase 4, the potential "candidate themes" were discussed with the second author, checking the codes and revising them in relation to the theme and their meaning, addressing researcher triangulation of data [17]. This enabled themes to meld together to create new, more inclusive titles. In Phase 5, themes were refined and named as presented in this article. The working titles were then transformed into defined headings that captured the true essence of the main themes, and data was summarised by combining descriptive narrative with pertinent data extracts. Phase 6 included the third author in the process of writing up, reflecting upon the analysis and writing the final research report. Finally, the three authors met on MS Teams for final adjustments and to agree on the final report.

2.6 Reflexivity

Braun and Clarke [9] affirm that reflexivity in thematic analysis consists of "locating yourself" (p.14), including awareness of both philosophical and theoretical assumptions that inform the research and also personal positions, who the researcher is and the lived experience that shape or inform the way the research is conceptualised and conducted [9]. Reflexivity was adhered to throughout the study to aid the researcher in maintaining an open stance by being observant, attentive, and sensitive to the expression of experiences from participants [19]. Therefore, the first author recognises her positioning including experiences of working with autistic people and previous knowledge informed by prior literature reviews that obviously shaped the research. As recommended by Braun and Clarke [9], a reflective research journal was utilised to facilitate awareness and new insights.

Both the first author and the second author (research supervisor) are females and identify themselves with the gender identity of women being underrepresented in the literature of autistic women. The third author identifies himself as queer and advocates for occupational justice of underrepresented and marginalised groups.

2.7 Ethical considerations

The study was approved by the Leeds Beckett University Ethics Co-ordinator (LREC) and informed signed consent was obtained from all participants before taking part via email. The researcher followed a person-oriented ethical approach for research with autistic people laid out by Cascio et al. [12]. An information sheet and a copy of the interview schedule were shared with participants. Participants returned a signed consent form and their demographic information to the researcher. The consent and interview processes were designed to be accessible and maximise participants' decision-making abilities, and ease any anxieties related to taking part. Participants were provided with a comprehensive information sheet, encouraged to ask questions, and given the interview schedule to review in advance. A quiet, clutter free background during the interviews was ensured with consideration of potential sensory and processing needs, and participants were invited to have a supportive person present at their interview (one participant opted to do this). The researcher also liaised with autistic advocates who provided feedback on important ethical considerations which the researcher remained sensitive to throughout the research (see Appendix 2). All participants were assigned a pseudonym to ensure anonymity. No compensation was provided for taking part however this may be reconsidered in future research as it may have presented further barriers to participation for socio-economic reasons. In accordance with University policies in line with GDPR, data were stored on the first author's OneDrive account (password encrypted) which was deleted after student course completion.

Table 1 Participants demographics (n = 8)

Participant pseudonym and age	Age diagnosis received (years since diagnosis)	Reported mental health / diagnostic history	Educational qualification	Employment status	Relationship status/living situation	Assessed by
1. Jen, 29	27 (2)	Borderline Personality Disorder diagnosis (BPD; misdiagnosis). Co-occurring PTSD. Mental health declined very rapidly around the age of 11	MSc in a Health Care Profession (current)	Student	Single, Living alone with two pet guinea pigs	Autism assessment service
2. Amy, 31	30 (1)	Anxiety since early childhood. Depression from age 13 with suicidal thoughts. No intervention. Diagnosed with OCD 2 years ago (pre autism diagnosis)	MA, MSc, currently completing PhD	PhD student. Research assistant and student mentor. Previously an English and Special and Social Needs teacher in secondary school	Engaged, living with partner and pet dog	Adult autism referral service
3. Amanda, 39	31 (8)	Depression and anxiety during early childhood, official diagnosis at age 12. BPD (misdiagnosis, later replaced with autism). Complex PTSD	GCSE	Unable to work since 2008	Single, living alone with pet dog	Clinical Psychologist at specialist service
4. Sally, 65	63 (2)	Lifelong anxiety. Treated for depression during 40 s	BSc in a health care profession	Part-time inpatient health care setting	Divorced with 3 adult children Living alone in own home	Adult Autism Diagnostic Service
5. Cathy, 70	61 (9)	None	Masters	Retired social work manager, still works as voluntary social worker (still registered) supporting autistic adults	Married, living with husband and pet dog	Specialist service
6. Charlotte, 39	38 (1)	Within the interview stated previously diagnosed with chronic fatigue and has physical disabilities	Masters	Unemployed due to physical disability	Single, living with mum and two pet cats	Clinical psychologist
7. Holly, 60	57 (3)	Depression at age 26. Lifelong obsessive personality disorder	PGDip	Self-employed counsellor	Living with long-term partner	Clinical psychologist
8. Sarah, 34	27 (7)	Anxiety and panic attacks in early secondary school. Depression began later in secondary school. BPD diagnosis around 26, before autism diagnosis	Completing a Masters	Charity for autistic adults	In a relationship, living with 2 cats and partner	Neurodevelopmental service

2.8 Findings

Table 1 presents the characterization of participants according to demographic information.

Three overlapping themes with accompanying subthemes were created during data analysis. In Theme 1, participants expressed how their volition was disconnected in terms of their needs and the influences of the environment, resulting in difficulties in unmasking themselves and adapting their behaviour to survive (subthemes). Theme 2 expresses participants' difficulties in balancing their occupations including time to care for themselves, in relation to work and the role diagnosis played on self-acceptance and the ability to self-advocate (subthemes). Finally, Theme 3 describes how acceptance worked as a protective factor related to the social support they received or not. These themes and subthemes will be described in depth as follows.

2.9 Theme 1: disconnection from one's own volition

"I couldn't understand myself. I didn't know why I was - I was struggling so much." (Jen).

All participants described a degree of disconnection from their wants and needs through personal and environmental influences, especially in their formative years. Experiences of early marginalisation and being problematised by those around them, paired with a lack of insight and "unknowingly" coping with sensory and processing differences led to self-schemas of defectiveness or difference depending on their level of self-acceptance (see Theme 3). Being undiagnosed and deeply ingrained camouflaging strategies reportedly contributed to feelings of not knowing oneself in multiple systems, for example, the family system, educational system or workforce, or the healthcare system. Holly explained she believes she would still be selectively mute if her mother hadn't threatened to abandon her for not speaking and so she learned to betray her own preferences for survival and attachment needs. Sarah describes the danger of being encouraged to ignore your own preferences:

"...it ends up being that you don't realize where your boundaries can be because no one has really taught you- you are allowed to set boundaries in certain places, and you don't have to do certain things with people." (Sarah).

Some described a sense of passivity and a lack of agency around big life decisions. Sally described how she "fell into" her 35 year career in critical care nursing. Amanda, though an avid reader, left school at 16 due to a lack of belonging and support, being labelled as a "bad child" for "never using" her intelligence. Post-diagnosis, she understands this as an executive functioning difference which impacted her ability to organise herself in the school environment. She describes a lack of guidance and becoming passively swept up in societal expectations:

"...coming from a working-class background at that time, all women were seen to do was go into the care profession. So that's what I did, off I went, straight into a nursery. I didn't really want to do it." (Amanda).

There was a sense among participants that an element of "luck" is involved if an autistic individual finds an occupation that is suitable to them:

"I think if autistic people reach their potential, it's by accident. They just so happen to be in certain jobs that they can reach- reach their potential or they work for companies - which is very rare- who employ a lot of autistic people." (Sally).

Amy described how her sensory processing differences compounded the way she was encouraged to overlook her own needs:

"Interoception I think it's called..." "...the relationship between your mind and your body or something like that; like, knowing you need the bathroom, like, feeling pain, knowing when you're hungry. Like, I struggle with some of those cues as well." (Amy).

From facial expressions to accusations of falsely leading on romantic partners, participants describe their behavioural differences as often being interpreted negatively by non-autistic others; having their motives and values challenged often, and even hostile or invalidating experiences when seeking support. Charlotte described feeling "guilty" during doctor's appointments due to her communication needs; she can "shut down" when overwhelmed and has been accused of being "drunk or on drugs" by her doctor. She advised she will not go to the doctor unless "desperate", similar to Amanda who reported having a UTI for over a year due to barriers accessing healthcare.

Pre-diagnosis support was often inappropriate, exacerbating feelings of disconnection and inexplicable defectiveness. Amy and Sally describe how undergoing Cognitive Behavioural Therapy (CBT) without addressing their unmet needs was detrimental to their well-being:

"...that's incredibly invalidating because essentially the message is 'well, if you try a bit harder, it will work' kind of thing. So, when it keeps not working, you're like 'Oh my God, like I'm so anxious and I'm doing my best and it's not good enough.'" (Amy).

"But obviously nobody knew I was autistic when I was having this CBT. ... so that maybe didn't necessarily work with CBT... from people that don't know you're autistic. Usually they change the CBT to suit autistic people, don't they? Because CBT doesn't necessarily work for people with autism" (Sally).

2.10 Subtheme 1.1: struggling to unmask

Participants described how masking mechanisms had become so ingrained that they struggled to identify their natural inclinations after diagnosis. Charlotte put it as "a period of questioning yourself, as to what was masked and what was genuine." Holly, Amanda and Amy describe a persistent feeling that they do not belong with other people, that they "fit nowhere" or that it is "impossible" to fully unmask around others as it "wouldn't be accepted". Cathy believes she may have adapted her stimming behaviours to be more socially acceptable over the years. Jen describes environmental pressures to continue consciously masking despite the debilitating consequences:

"I very much wouldn't have been able to get to the point I am today without masking. I don't think I would have got onto this course." "I'm on multiple migraine medications and I know what it is. It's masking." "I hate that we live in a society where autistic people have to mask to be able to function..." (Cathy).

Participants all acknowledged that a lack of awareness or acceptance of difference in society had a major role in their "inauthentic" behaviours developing and outlined a need for professional support in "undoing what was learned". Amy highlighted that the change she would like to see is "entangled" with a change that "needs to happen for women generally in society" as they are "held to impossible standards". Further, she echoed the sentiment of all participants by calling for "departmental policy level" action in terms of spreading awareness of autism when it comes to early identification and providing support for less visible autistic people.

2.11 Subtheme 1.2: being in survival mode

Participants describe early experiences as "surviving" a "battle", "struggle" and "hell", consistently being "overwhelmed" or "bubbling" under the surface due to heightened baselines of anxiety related to social, sensory, and communication difficulties and overwhelm. Feeling at capacity from stimulation and shutting down was not uncommon. Experiences of "general cruelty" and relying on or trusting bad actors throughout their lifetimes combined with a lack of understanding of the mechanisms with which to engage with a society "set up for neurotypicals" resulted in a justifiable sense of vulnerability for participants:

"...the majority of late-diagnosed autistic women have been traumatized in some way or other, and no one seems to take it seriously or understand what's actually happened to them." (Sarah).

Camouflaging was often employed by participants to reduce visibility. All participants cited empathy as a personal strength which was often related to their own experiences of rejection, bullying, being taken advantage of by false friendships, or emotional abuse at the hands of parents or partners. Further, participants outlined aspirations to simply protect either themselves by withdrawing from the outside world, or others similar to them, through advocacy.

2.12 Theme 2: striving for occupational balance

"I'm at the point now I'm thinking of easing down...and wanting- this is interesting- wanting more out of life because I still can't balance, you know, working and doing stuff for me, it's still one or the other." (Holly).

In terms of self-care, leisure, and productivity, participants described experiences of having a persistent struggle to maintain "balance" in their lives. Self-care was an area that participants often even struggled to understand as a question, and there was a general sense that it "went out the window" at certain times in their lives.

Participants sometimes lost connection with important occupations which was associated with the occupational opportunities and engagement expected in British schools and culture. Jen discussed how early experiences in P.E., where the competitive environment was ‘too chaotic’ for her sensory differences, led her to avoid exercise until she discovered walking and hiking to be an important part of her self-care and leisure occupations post-diagnosis.

Holly described how pre-diagnosis, she used to spend her weekends sleeping to recover from the work week and now manages her “spoons of energy” for communication by being self-employed which she reported “dramatically” reduced her earnings.

2.13 Subtheme 2.1: Socio-cultural emphasis on productivity

All participants but Cathy outlined experiences of “colossal” autistic burnout due to a lack of balance. Cathy explains:

“50 odd years ago when I was young, the expectations were very, very different to what they are today. So, for me, not working for a while was completely, you know, it wouldn't have been like, ‘Oh my God, she doesn't work.’ Whereas nowadays you, you know, there's this huge expectation that you have to work and have a career and a lot of people really, really struggle to hold down a job”. (Cathy).

Amy speaks of how her life has been an endless “dysfunctional” goal-oriented struggle where she has never been able to enjoy the process of certain major achievements, such as finishing her master's degree, describing it as a fleeting form of academic “validation”. Further, Amy and Charlotte described how their “love of learning” was belittled by those around them, recalling “derogatory” treatment for being a “perpetual student”. Amy expressed worry about finishing her Ph.D. which currently very much suits her needs due to reasonable adjustments and having a supervisor who happens to have autistic children. Similar experiences resonated with all participants around societal shaming which they often internalised and responded to by overcompensating and burning out:

“...before I was diagnosed, you have words thrown around like lazy or a fussy eater or delicate, shy, quiet, but then they're the sort of adjectives that assume I had a choice in that. I wasn't being fussy. I wasn't being lazy. I was exhausted.” (Charlotte)

Jen reported a family breakdown occurring when she refused to go to school as a child as there was “a big government, clamp-down on school absences, taking parents to prison” instead of supporting struggling families. Amanda speaks of how “growing up in the 80 s and 90 s, the awareness just wasn't there—there were very different social attitudes and education”. She was afforded very little attention by those around her who didn't give her the time, prioritising getting her back to school rather than attending to her emotional needs:

“I was let down by a lot of systems. I was diagnosed with depression and anxiety at 12. ‘There you go. Have these antidepressants,’ ‘cause I couldn't get on the bus to go to school.” “No one wanted to know. No one thought to ask me”. (Amanda).

2.14 Subtheme 2.2: Double-sided power of the diagnosis

Participants reported benefits to receiving a diagnosis as it provided insight into long-standing difficulties and facilitated a level of self-acceptance and the ability to strategise and self-advocate more effectively. All participants reported receiving no intervention post-diagnosis, with some receiving inadequate resources tailored to “parents” of “small, white, middle-class boys”. Jen said of her experience:

“It was a bit like somebody being told ‘You've got asthma, but we're not gonna tell you anything about what asthma is or how to cope with asthma, but it is going to affect the rest of your life. And without you knowing, it already has affected all your life and every aspect of your life... But we're not gonna tell you about it.” (Jen).

All participants, even those with higher levels of self-acceptance, advised that it is not wise to share the diagnosis with everyone and it must be used strategically within the social climate, describing it as difficult to “make yourself even more vulnerable” having already experienced such little understanding pre-diagnosis. Participants often had experiences of being told they “couldn't be” autistic due to widespread stereotypical understandings. Most participants had only disclosed their diagnosis to one or two people close to them or other autistic people.

Practically, participants report that reasonable adjustments at work have been helpful but there is still a stigma attached to certain needs that are poorly understood e.g., Sally and Jen reported sensory sensitivities to noise,

textures, or lighting when it comes to offices and uniforms. The interviewing and hiring process was highlighted as particularly difficult for participants and should be adapted to allow “people with different access needs to show their potential”.

Participants all benefited from doing their own research post-diagnosis and some found online communities provided a sense of belonging. Further, participants often reported suitable support services being out of their geographical reach. All participants called for societal-level change and action to improve their quality of life through self-awareness and social acceptance:

“...support and public awareness, knowledge, diagnosis and education, because for me, I need knowledge before I can explain things to myself or others, so being unable to advocate for myself impacted me socially, academically and economically.” (Charlotte).

2.15 Theme 3: acceptance as a protective but dependent factor

“...they're not getting the support they needed. I've had to go through private counselling because my partner now works in private healthcare, so we get sort of it covered. And I went through... kind of saying, like- I don't know, I keep getting told I've got PTSD.” (Sarah).

Participants describe how the diagnosis was helpful as it provided a lens of understanding, not only to them but also to those around them. The level of acceptance of difference within the participant's family influenced their own ability to accept themselves and their ability to ‘get on with’ life, pre-diagnosis. Those who had familial support particularly referenced the role of their mothers in their ability to self-accept themselves. Holly, who experienced emotional abuse from her mother, explained she “luckily” benefited from competitive swimming at school which was a socially “accepted” occupation by her peers. Those who reported rejection within their family and their wider social environments reported more difficulties in self-acceptance post-diagnosis.

Of the participants who were the longest diagnosed, Sarah and Cathy self-identified as “lucky” regarding their socio-economic standing, life chances, and support systems. Both described a level of acceptance pre-diagnosis of “being different”, whereas Amanda who self-identified as working class, reported early familial breakdowns and a total lack of insight and disconnection pre-diagnosis. Of these participants, Amanda reported persistent “pain”, “anger”, and times when she still struggled to accept her situation and past. Amanda was an early school leaver despite elevated intelligence, she has been unable to work since 2008 and reports a persistent lack of present belonging where it is ‘impossible’ to unmask around others. Sarah and Cathy both benefited from more supportive social and economic environments pre- and post-diagnosis and diagnosis for them facilitated their discovery of a new, autistic community, fostering a sense of belonging and ability to advocate for others. Sarah highlighted the inequity in experiences well, describing why she decided to set up her own charity for others like her (as expressed in the quote at the beginning of theme 3).

2.16 Subtheme 3.1: Grieving process over lost opportunities and lack of support

“There's a huge grief there. There's huge pain. I'm so sad for like the child that I was. So yeah, I think definitely some sort of therapy would really help autistic women to sort of accept and begin to let go of the pain and the grief of what they didn't get when they were kids.” (Amanda).

Holly and Jen expressed feelings of loss around what were important occupations to them due to lack of support for their needs; Holly wished she had gone further with competitive swimming and Jen gave up her spot in the Royal Academy of Music due to unmanaged and neglected sensory overload:

“...I really lost my confidence after that and really that was the end of music for me. I mean, I've still got my flute and everything, but I've never- I've not really picked it up since...” (Holly).

There is a common regret for not having the knowledge as a child to help participants cope and understand difficult situations throughout their lives:

“...if I'd been diagnosed, obviously as a child, these - I suppose, I probably still would have had these trillions of mini traumas, but you would have understood why.” (Sally).

3 Discussion

The research aimed to explore, through qualitative interviews with autistic women who received a diagnosis in adulthood, the internal and external factors that influence occupational identity development. In doing so, the research sought to identify the barriers and facilitators to their engagement with meaningful occupations.

The findings support Phelan and Kinsella's [62] proposal that conceptualisations of occupational identity have long overemphasised individual determination and underestimated social influences. Within occupational identity theory, occupational competence refers to an individual's capacity to successfully maintain a pattern of *doing* within their occupations and affects the success of occupational adaptation in the face of occupational challenge [69]. Occupational adaptation refers to the strategic deployment of actions, not only as a reaction to a disruption or transition but as a conscious everyday strategy to advance one's occupational choices [59].

In line with critical autism studies, the findings of our study suggest that autistic women are experiencing occupational injustices within society, including early marginalisation and alienation [68, 70]. The findings suggest this often leads to a detrimental cycle of unsustainable occupational adaptation (e.g., camouflaging to expand one's occupational choices) and its associated negative outcomes on occupational competence (e.g., autistic burnout related to societal rejections and increasing demands on productivity) [66]. Importantly, it is evident from the findings that participants and their occupations are inseparable from their environments; it was outlined that the social environment interacts with participants' social and neurological differences to influence occupational engagement and processes of occupational identity development.

Occupational identity construction can lead to positive or negative consequences for the individual [29]. Positive consequences include a sense of contentment, confidence, competence or acceptance, whereas negative consequences include a sense of discontent, uncertainty, incompetence or alienation. Not meeting perceived social standards for *being* and *doing* is suggested to result in these negative consequences, while finding one's space in broader society (*belonging*) is important to one's sense of self [29]. Our findings suggest that receiving a diagnosis may facilitate a positive shift in participants' occupational identity. Further, they are in line with other studies indicating that the realisation of a diagnosis facilitates self-acceptance and that personal acceptance as part of one's identity mediates the relationship between self-esteem and mental health difficulties [16, 27, 46]. We also emphasise the pervasive influence that dominant socio-cultural values have on the extent to which self-acceptance pre- and post-diagnosis may occur. Our findings align with research that suggests that a dominant culture influences factors relating to family life, occupational and social opportunities [57]. These cultural influences were most evident by differences in socio-economic standing and the outcomes among the three longest-diagnosed participants (see Theme 3).

Our findings contend with literature that suggests camouflaging strategies may be trauma-based coping mechanisms [30], and an effortful form of occupational adaptation that reflects a gap between how autistic women behave and their true inclinations, limiting the autistic individual's true potential within society [56]. Findings from a previous study conducted in the United Kingdom with 262 autistic people identified gender differences regarding camouflaging, where autistic women were shown to more frequently endorse "conventional" reasons for its use, for example, getting by in formal contexts such as work. Moreover, the study concluded that camouflaging in different contexts and 'switching' in others was related to poor mental health [11]. Therefore, the development of strategies that could support autistic women to do and be themselves to reinforce their occupational identity plays a key role in future actions. Women currently coming to learn that they are autistic may benefit from support in uncovering their own occupational narratives which are understood to bring coherence and meaning to one's occupational identity [41].

A largescale survey highlighted that dehumanising attitudes towards autistic people prevail among non-autistic individuals [67], indicating that there is much more work to be done in terms of awareness and creating compassionate and tolerant communities. Occupational therapy as a profession must prioritise raising awareness of neurodiversity and reducing deficit-laden language relating to autistic people, particularly among education and healthcare professionals, to facilitate not only early identification but also an appropriate response to a person's differences. Stein et al. [78] found that autistic adults reported sensory and communication strategies to be helpful but rarely used during primary care visits and further, expert primary care providers reported using said strategies more frequently than novices. Thus, staff training can seek to normalise alternative strategies of communication and regulation, promoting more accessible care for autistic individuals. Initiatives such as community talks or youth mentorship programmes like Girls Night Out can serve to educate communities [75]. Communities more tolerant of differences may enable autistic girls and women to naturally reduce (or prevent the acquisition of) their camouflaging behaviours, allowing

them to express their occupational identities authentically in their communities, work, and social settings. Theme 2 and 3 described experiences of disclosure, sensory issues at work, turning to self-employment due to the unsuitability of work environments, and the need for workplace adjustments.

Our findings suggest that the neoliberal ideology that dominates the socio-cultural environment in Britain is promoting a framework of 'self-empowerment' that ultimately fails to acknowledge the social context in which an individual makes choices and acts upon their social environment [18, 70]. This is proposed to perpetuate the negative consequences on the occupational identity of not only the individuals in question but likely those around them that are reported to consistently project negativity or cruelty onto participants rather than compassion. Research indicates that neoliberalism is shown to result in a sense of social disconnection, competition and loneliness within society [7]. Neoliberal tenets of prioritising productivity while individualising social problems is common in stereotypical representations of (usually male) autistic individuals in media; often portrayed as dependents who have difficulty functioning in modern society and must ultimately 'overcome' through personal initiative [2]. This is not dissimilar to the notion of 'white feminism' (or 'corporate feminism') so-called due to its neoliberal underpinnings that ignore intersectionality by promoting individual achievements that do nothing for the collective feminist movement that calls for a structural reality change to improve the basic standard of living [18].

Hammel [28] outlines the danger of echoing individualistic values, as neoliberal underpinnings can lead to the assertion that all individuals have autonomy and free will to choose and shape their everyday occupations, implying occupational choice is the product of individual volition and rational deliberation. Indeed, this is not what our current findings suggest (see Theme 1, Sub-theme 2.1). Rather than further promoting neoliberal ideals, such as the promotion of self-care occupations as an individual's responsibility to 'recover' from daily life, it is recommended to recognise the societal structures that delegitimise the lives of neurodivergent women by taking up active advocacy roles in public health and politics to promote collective health through improving the basic standard of living according to the social determinants of health [49].

4 Implications

Occupational Science research has an important role in combatting the systematic oppression perpetuating the trauma and stigmatisation being experienced by autistic people in the first instance. The research in Occupational Science has, therefore, a mission to stress the borders, uncover and challenge scholars' unconscious biases and misrepresentation of autistic people that inform current research in the discipline [45]. In the same direction, our research sheds light on discussing women's experiences, re-examining androcentrism in autism research, and introducing the theme of occupational identity and the lived experience of women later diagnosed with autism.

From the Occupational Justice lens, our research demonstrates one way to be client-centred and activist against injustices by employing a qualitative method to explore people's experiences of injustices [81], describing participants' possible imbalance and marginalisation. Individuals are intimately connected to societal and environmental contexts that are, too, in a perpetual state of change [85], and occupational therapists have a role in guiding this inevitable change in a direction that benefits public health; through the promotion of the equitable distribution of societal resources [33]. Practitioners could work with autistic people collaboratively and advocate for them in different environments such as schools, workplaces, health and social care settings and different organisations to reduce the advocacy burden where appropriate. The findings suggest that the inequitable distribution of the social determinants of health, impacting early childhood development, education, social support, and access to healthcare [49] contributes to inequitable health outcomes for participants that need further research.

On an individual level, a trauma-informed approach to assessment and intervention is recommended once an autism diagnosis is being considered among these people. Snedden [76] found that the Canadian Model of Occupational Performance and Engagement [64] was an effective model to aid in reshaping client identity and helped promote post-traumatic growth and recovery from difficult situations. Women currently coming to learn they are autistic may benefit from support in uncovering their own occupational narratives which are understood to bring coherence and meaning to one's occupational identity and impede or focus occupational adaptation [41]. That is, occupational therapists have a role in the grieving and acceptance process highlighted by participants (see Sub Theme 3.1) so these women may come to understand and accept their past, make more informed choices around their experiences of camouflaging, and forge a present and future which is proposed to lead to more positive consequences related to occupational identity. Using assessment tools that focus more on internal states than on external behaviours is recommended [75].

5 Limitations

A limitation of our study was that we did not have an autistic researcher in the team, however we consulted an autistic person for expertise for the research project including the research questions. Socio-economic demographics were not collected and the fact that all participants presented as white British must be highlighted as this may indicate further cultural barriers to awareness of autistic people or accessing appropriate healthcare. Moreover, interviews were conducted at one point in time, and only on MS Teams which could limit the amount of data that informed the lived experience of participants. Member checking of transcripts were not utilised due to time constraints of a masters research project. Although we recognise these limitations, we emphasise that this is the first empirical study focused on the occupational identity of women late diagnosed with autism. Future studies should also consider race, and gender identity as part of diversity that expresses who they are and has implications on their occupational identity as occupational beings.

6 Conclusion

We presented the first empirical Occupational Science study that focused on the lived experiences of adult autistic women. Our research has outlined that social environments and dominant socio-cultural values possibly influence the subjective experience of occupational identity of late-diagnosed autistic women. As scholars and practitioners, we have a duty to become aware of and challenge longstanding structures and systems in place that may continue to disadvantage and imposition already more vulnerable, less visible, and minority groups within society. Our study provided a platform for the voices of an often overlooked and marginalised group of people within research which has provided valuable insight into the mechanisms of their occupational identity development. Findings demonstrate our need to support a shift in clinical and societal attitudes towards understanding and valuing the diversity of autistic women. Neoliberal underpinnings of individualistic and ableist ideals perpetuated within society and practice are harmful to these individuals and must be addressed to tackle the health inequities being experienced. Political action is highlighted as a necessity for collective health promotion through improving the basic standard of living according to the social determinants of health.

7 Plain community summary

We interviewed 8 autistic adult women in the United Kingdom, intending to describe and understand the impact of later diagnosis and how it affected their lives. This included what they could do (for example, studying, working, relationships with others) and who they are. We analysed the interviews to create 3 themes. Participants felt disconnected regarding motivation and balance of what they could do in life. Acceptance of the diagnosis of autism appeared to be helpful. We found the need to work together to promote health and to improve the basic standard of living.

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Author contributions JL researched literature and conceived the study. AM was involved in supporting JL with protocol development, gaining ethical approval, patient recruitment and data analysis. JL wrote the first draft of the manuscript. AM and DC reviewed and contributed to refining data analysis and revising the final draft. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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Data availability statement The data supporting this study's findings are available from Leeds Beckett University, but restrictions apply to their availability. These data were used under licence for the current study and are not publicly available.

Declarations

Ethics approval and consent to participate This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Local Research Ethics Coordinator – LREC (Application Number: Ref: 97541) by Leeds Beckett University.

Competing interests The authors declare no competing interests.

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