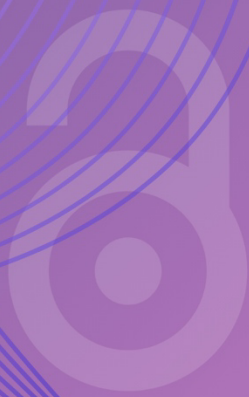


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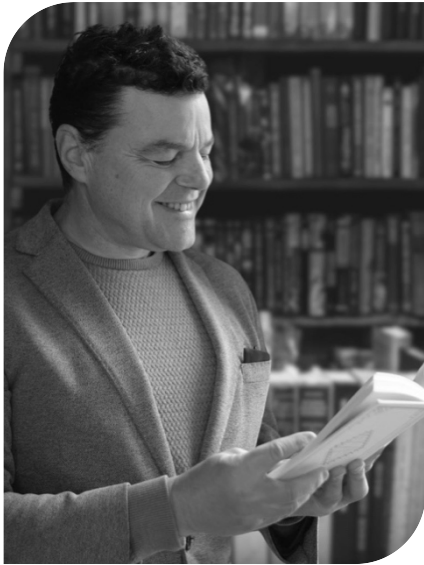
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FROM THE EDITOR

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Reclaiming Authority from the Authorities

This edition of NeuroConverse looks at the lived experiences of those who don't fit the prevailing standards of "normal". And its contributors ask a pertinent, and powerful, question:

Who holds the authority to define, represent, and act on disabled and neurodivergent experience, and how might that authority be equitably redistributed – and under what conditions of accountability – so that people long treated as objects of professional knowledge and curiosity are recognised as both human beings in their own right, and authorities on their own lives across public, clinical, and institutional domains?

In their differing ways, and from innovative new angles, each of the papers discusses questions about epistemic authority: who gets to say what an experience means, what constitutes a problem, what support is needed, and what a good outcome looks like. They argue that that inclusion is not achieved simply by raising awareness, providing support, or inviting participation after the important decisions have already been made; it depends on (and reflects) whether institutions are prepared to redistribute authority: to listen differently, redesign practices, share authorship, and treat disabled and neurodivergent people as knowledge-makers rather than as subjects, beneficiaries, inspirational examples or evidence of institutional virtue. Parental social media, organisational "impact stories," and educational case discussions all make neurodivergent people visible, but on terms set by the storyteller. The person at the centre is cast as victim, the storyteller as rescuer, and systems as persecutors. The argument, at its very heart, calls for an urgent and human-centred transition from tokenistic inclusion and 'benevolent intervention' towards something resembling radical epistemic justice, shared authority, authentic permission, and systemic accountability.

In making this case, the papers orbit around various centres of gravity: deficit vs expertise; isolation vs recognition; deflection vs accountability; method vs ethics; and voices vs rights. In this universe, disabled and neurodivergent people empower themselves, transforming from objects of interest into experts whose articulate, strategic and unique self-knowledge emerges only when the right conditions – such as predictability, trust, peer-led design, and the right to refuse – are structurally enabled.



The case is made that deficit framings, institutional habits, and well-meaning storytelling combine, no matter how well intentioned they are, to place disabled and neurodivergent people at the margins of their accounts of their own lives. But true inclusion requires dismantling the assumption that institutional norms are neutral, fixed, or in some way objective standards to which individuals must conform and into whose boxes they must fit. When participation is designed around institutional norms, institutions tend to hear what their existing categories are most likely to accommodate. When participation is designed around trust, accessibility and shared authority, new knowledge becomes possible.

This asks the question of how best to centre the neurodivergent voice – and the often vulnerable person whose voice it is – and undermine the damaging power dynamics that have been ingrained into much of the research. How, in other words, can neurodivergent people actually be heard, and what it means, in ethical terms, to actually be heard.

It turns out, in reading this edition's contributions, that much of what we think we know about disabled and neurodivergent people is actually knowledge about them, rather than their knowledge. There is a world of difference between including someone's experience as data and recognising that that experience itself is authoritative. And questions of what might change once people speak become central to the notion of true inclusion. What might we, as a society and as a society of researchers, end up giving up – intellectually, ethically, socially, and normatively – when we truly hear the voices of those we claim to listen to?

Marlon Bloomfield



CONTENTS

01 - 12 ‘What I Would Like to Say...’: The effectiveness of the BU PIER Community Researcher Model in capturing the voices of disabled people’s experiences of cancer services in the UK

Katie Munday, Roseanna Tansley, Amanda Durrant, Stevie Corbin-Clarke, Katherine Jupp, Mel Hughes

**13 - 28 Same Food as Self Care:
A Community Perspective on Autistic People’s Relationships with Same Foods**

Scott Neilson, Laura Hellfeld

29 - 41 Dismissed as just a “chatterbox”: Examining Childhood Symptomatology, Educational Costs and the Effects on Mental Health of Delayed Diagnosis of ADHD in Women

Leanne Chrisostomou, Merijn Schellekens



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'What I Would Like to Say...': The effectiveness of the BU PIER Community Researcher Model in capturing the voices of disabled people's experiences of cancer services in the UK

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Abstract

Disabled people experience persistent inequities in accessing cancer screening, diagnosis, treatment, and care in the UK, shaped by structural ableism and inaccessibility. These inequities contribute to delayed diagnosis, reduced uptake of screening programmes, and poorer experiences of cancer care when compared with non-disabled populations. Despite this, disabled people remain underrepresented in health and social care research. The BU PIER Community Researcher Model was applied within a 10-month pilot study, 'What I Would Like to Say...', in which data were generated through four face-to-face arts-based workshops involving 45 disabled participants. Creative methods were used to support accessible engagement with a sensitive topic, enabling participants to share their experiences through handprint artworks and informal semi-structured discussions. Data were analysed using collaborative thematic analysis integrating lived experience, clinical, and academic perspectives.

Three key themes emerged: the importance of accessibility, the value of fostering a relaxed, supportive environment, and the need for participants to feel heard and valued. These processes enabled us to co-create suggestions for improving practice in asymptomatic screening and primary cancer care. The paper concludes that the BU PIER Community Researcher Model offers an effective approach for inclusive research with disabled communities with the potential to inform improvements in equitable cancer service provision.

Keywords: Community Research, Participatory, Disabled, Cancer, Primary Care

1. Introduction

Disabled people face significant barriers in accessing cancer services due to interpersonal ableism, stigma and discrimination, and systemic structural factors including physical inaccessibility (World Health Organisation, 2023). Disabled people face various barriers when trying to access asymptomatic screening and primary cancer care in the UK, including invalidation of their needs, being misunderstood or ignored, and being perceived as a 'low priority' within healthcare (Gibson & O'Connor, 2010; Sakellariou et al., 2019). These issues lead to people with disabilities being underdiagnosed and undertreated at higher rates than non-disabled people (NHS, 2022).

Individuals with learning disabilities and mental health issues encounter more obstacles in accessing cancer screening services, resulting in more instances of late-stage cancer diagnoses (Heslop et al., 2022; Satgé et al., 2014). Research by Mencap (2019) found that only 19% of people with a learning disability engaged with cervical screening, compared to 77% of all people invited. Similarly, only 33% of people with a learning disability engaged in breast screening, compared to 70% of all people invited (Mencap, 2019). Forgoing screening means many learning-disabled people have their cancer discovered at later stages, with 46% of all cancers in adults with learning disabilities being diagnosed at stage IV when the cancer has already metastasised to other parts of the body (Heslop et al., 2022; Satgé et al., 2014).

As the population ages and more people live with cancer and disabilities, it is important that we understand and respond to the needs of this group to ensure services are accessible, appropriate, and affirming. This is especially pertinent as disabled people diagnosed with cancer are also more likely to report low satisfaction with care and have higher cancer-specific mortality compared with their non-disabled counterparts (Cuypers et al., 2020; Tosetti & Kuper, 2023). People with disabilities consistently report receiving poorer quality cancer care, including delays in treatment, excessively invasive treatment, and less access to pain medications and state-of-the-art care (Tosetti & Kuper, 2023).

In addition to cancer care inequity, disabled people are often overlooked in health and social care research and public health interventions. Despite their lived-experience expertise, disabled people often remain excluded from health and social care research due to inaccessible and limited opportunities to participate, and activities that fail to recognise the barriers to engagement (NIHR, Include Project, 2020). Building capacity within the voluntary and community sectors to conduct research with their communities is one approach to improve equity in health and social care research and provision (McDonald & Raymaker, 2013). Community organisations and charities have well-established relationships within their communities, often making them well-placed to conduct research that reflects the needs of their members (Department for Digital, Culture, Media and Sport, 2022). When used with disability communities, participatory approaches could be more accessible and inclusive, with participants respected and valued as partners in knowledge creation (Blumenthal et al., 2013; Lawson et al., 2015; Isaacs et al., 2020). One such approach is the Community Researcher Model used by Bournemouth University Public Involvement in Education and Research (BU PIER), which supports and mentors people with lived experience to undertake research. This article reflects on the effectiveness of the BU PIER Community Researcher Model on capturing and representing disabled people's experiences of cancer care, and shares recommendations to improve practice within asymptomatic screening and primary cancer care for disabled patients.

1.1 A note on language

Language can be a powerful tool to express an individual's experience, as well as perspectives towards disability and identity (Bottema-Beutel et al, 2021). Participants and community researchers used a mixture of language to express their disabled embodiment and experiences. Therefore, we use a mix



of identity-first (i.e. disabled person) and person-first language (i.e. person with disabilities) to best represent everyone involved in this project.

2. Approach

The 'What I would like to say...' project involved two disabled community researchers (K.M. and R.T.) to carry out creative and engaging workshops and interviews with 45 disabled people, with the support of Bournemouth University's PIER team (K.J. and S.C-C.), and a cancer Clinical Nurse Specialist (A.D.). This pilot project was a part of the 'Whatever It Takes — Cancer Care for Everyone' programme (Wessex Cancer Alliance, 2023).

The aims of this pilot project were threefold: 1) to build capacity within a community for engaging and leading on inclusive research; 2) to understand and share the cancer service experiences of disabled participants across Wessex; and 3) to further develop the BU PIER Community Researcher Model. We have shared the specific cancer care experiences of participants elsewhere (Tansley et al., 2024). In this article we focus on how the BU PIER Community Researcher Model built the capacity of the community researchers and has led to further work to improve access of cancer services in both academic outputs and applied practice in Wessex hospital settings.

The BU PIER Community Researcher Model enables individuals who have personal experience with the subject being discussed to feel at ease in sharing their perspectives, while also fostering their confidence to take on roles as peer mentors and community researchers. The model follows eight principles:

1. Listening and insight gathering.
2. Leadership engagement and commitment.
3. Collaboration and community engagement.
4. Empathy and understanding.
5. Building trust through relationships.
6. Flexibility and person-centred approaches.
7. Awareness and education activities.
8. Cultural and perceptual shifts.

These principles have been developed throughout different projects (Hand et al., 2026; Hughes, 2025; Munday & Tansley 2026) and are based in the understanding of the differences between priorities and motivators in the system world and the lifeworld. Within the system world, research is often perceived as a clearly outlined process: objective and transactional, where participants supply data to researchers, often leading to an imbalanced power dynamic (Farr, 2018). In contrast, the lifeworld involves individuals collaborating on projects with their own motivations and desired results, with priorities generally stemming from values, relationships, communication, and everyday experiences (Green & Johns, 2019). The BU PIER Community Researcher Model was chosen for the current project as it involves lived experienced experts and community collaborators setting the priorities, while being assisted by the wider research team, shifting the conventional research power dynamic.

Cancer and healthcare (especially that which involves intimate care) can be difficult experiences to discuss. The psychological safety of participants and the research team was vital. Throughout the workshops, the cancer Clinical Nurse Specialist (A.D.), with her depth of cancer knowledge and connections to the NHS, supported participants and researchers through. A.D. ensured everyone felt supported whilst sharing their cancer service stories, and signposted when needed.



This study was carried out in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Bournemouth University (Date 21/10/22, No.45815).

2.1 Data Collection and Analysis

We used convenience sampling (Galloway, 2005), drawing on our networks of community connections across the Wessex region, including Autism Hampshire's Fareham Serendipity group; the Dorset Blind Association; the Multiple Sclerosis Centre Dorset; and the Bournemouth and Poole Lymphoedema and Lipoedema Support Group. These findings were supplemented by a semi-structured video call interview with a member of the Royal National Institute of Blind People recruited through purposive sampling (Patton, 2002) after they shared their experiences of local breast cancer care on national radio. Overall, we spoke to 45 people with a range of disabilities, ages, genders and experiences through four face-to-face creative arts-based workshops.

We decided to use an arts-based method to enable participants to explore their subjective experiences, feelings, and emotions (Leavy, 2020). These methods have proven useful when gathering data and disseminating findings, when exploring complex research topics where more traditional methods are not always sufficient (Holgate et al., 2012; Vaart et al., 2018). Due to the sensitive nature of our research topic, and to make workshops fun and accessible to groups with mixed abilities (Fenge et al., 2011), participants were encouraged to create a piece of art that represented them and their experiences of asymptomatic screening and primary cancer care. Creative workshops lasted up to two hours, with a semi-structured, flexible agenda. During the creative workshops, research team members spent time with participants listening to and capturing what they said using prompts such as 'what would you like to say about your experience with cancer services?', 'What has brought you comfort?' and 'what is your story?' as required.

We used thematic analysis (Braun and Clarke, 2021) to identify similarities and differences across participant experiences. After initial coding by all research members, codes and themes were explored and defined by K.M. and R.T. until an accurate reflection of the data, equally valuing lived experience and clinical and research expertise, was achieved. This ensured that lived experience, practice and academic perspectives were all valued.

3. Results

Participants shared workshop-specific insights around the themes of accessibility, being in a relaxed environment, and feeling listened to and valued, as well as recommendations for improving practice in cancer care. These results highlight the effectiveness of the BU PIER Community Researcher Model for capturing and representing disabled people's experiences of cancer care.

3.1 Accessibility

Adjustments were made throughout the process to meet individual access requirements. The team shared project information at one of the group's drop-in events. The group leader then visited Bournemouth University to complete their risk assessment and shared, "We don't have a community building, so we need to go to places for activities. Research needs to be a trade-off for the group to get a free accessible session [...] the payments towards travel costs really helped make a difference." Additionally, they shared that the room worked well as it was close to the accessible toilets and the lift, and they appreciated being guided by a member of the research team to the workshop room.

On the lead-up to engaging with Autism Hampshire, the community researchers reflected on their autistic lived experiences and offered the group more specific support, including a detailed outline of the workshop plan and a 'meet the team' document with photos and short bios of each research team member. An autistic participant shared, "The purpose of what you were doing and why you were doing it was all very clearly explained beforehand." The BU PIER Community Researcher Model allowed for



more connections between researchers and the participants, connecting through shared experiences was an important part of making the sessions more accessible and more fruitful.

3.2 Creating a Relaxed Environment

Creating and maintaining a relaxed environment with clear choices of *if* and *how* participants engaged allowed participants to “Really relax” and share their experiences on things they “Would not normally talk about”. One participant shared that the art process was a good way to “Express our emotions towards how we feel about our experiences with cancer services”. The Autism Hampshire group leader shared that having a creative activity to focus on enabled their members, “Who are often quite anxious with new people and new activities to really engage, and it really did translate into the message of ownership of the project.”

Figure 1: Participant's hand maps



Note. This figure shows a collection of hand map artworks from the creative workshops. The hands are individually decorated with pom-poms, sequins, feathers and colourful handwriting. The hands are set out to make a large heart shape against a stark white background.

The creative workshop design, often used within the BU PIER Community Researcher Model, was an effective, relaxing and joyful method to gain contributions from participants (many of whom were participating in research for the first time). Creative workshops allowed participants with different needs to join in at a pace and level which suited them, and small group sizes allowed participants to direct the conversation (Coemans and Hannes, 2017; Ørngreen & Levinsen, 2017). Creative workshops were a process of playful and often joyful experimentation, creating the conditions for comfortable sharing of experiences, appreciating participants as experts in their lived experience (Wang et al., 2017).

Another group leader reflected, “The team were fantastic at making everyone feel comfortable. I was amazed at how open and comfortable people were to chat with the team.” They shared that having autistic community researchers made the group feel more comfortable with sharing their experiences as they would “Understand what its like”. This shows the effectiveness of working with community



researchers who share identity and life experiences with participants. Community researcher R.T. reflected:

As someone with Crohn's Disease who has spent a lot of time in hospital and undergoing cancer screening myself, it was eye-opening to realise how much my own experiences resonated with what everyone else had to say. This helped me to both recognise where our recommendations should lie and to look inwards and understand that I was not in fact alone in my own experience.

3.3 Ensuring Participants Feel Listened to and Valued

Several participants shared that they felt listened to and valued, "[Members] had one-to-one attention; this is something the group really values and responds to, as they often feel that they don't have a voice." This one-to-one attention was possible due to the amount of research team members in the room, and the ability to use our different skills and attributes to engage people in a personal manner. The community researcher's have had previous experiences of engaging in research that was inaccessible, harmful or felt extractive and they did not want to replicate that, as K.M. reflected:

It was important to me that the sessions were as accessible as possible. I have been a participant in autism research which has been terribly designed and it made me feel invalid... I did not want our attendees to feel this way at any point in our journey together. I want other disabled people to feel listened to, to feel seen, cared for and respected.

One participant explained that they were happy to share their story, especially as it may help other visually impaired people in the future, "I felt listened to today... the more information there is, the better, even if it takes time to filter through." This participant was initially hesitant to come to the workshop due to their anxiety; however, with the support of their carer, they were able to attend and became increasingly comfortable engaging with the workshop. All groups reflected that they felt the workshop was worthwhile and they were happy to have contributed to the 'What I Would Like to Say...' project.

Figure 2: Visually impaired participant's hand map



Note. A large pre-printed hand. Words surround the highly-textured and colourful artwork. Phrases include: I feel unsafe; I feel white fury; care is predicated towards the normative body.

3.4 Recommendations for Improving Asymptomatic Screening and Primary Cancer Care

Facilitating accessible and relaxed workshop environments where participants felt listened to and valued allowed us to effectively capture participant's suggestions for service improvements with three key areas: compassion and reassurance matter; effective communication is key; make accessibility a priority.

3.4.1 Compassion and Reassurance Matter

Many of the participants shared that a person-centred approach would mitigate some of the anxiety they felt when engaging with primary cancer care. Recommendations for practitioners included:

- Provide clear information to patients of what to expect during the process, being mindful to reassure patients where needed.
- Take care not to rush patients through examinations to avoid depersonalising their experience.

3.4.2 Effective Communication is Key

Participants spoke of effective communication as being a core aspect of supporting their understanding during primary cancer care, supporting informed decision-making. Recommendations for practitioners included:

- Support patients to make informed choices through stronger collaboration between physicians and patients.
- Work across specialisms to ensure the right course of action that considers all aspects of a patient's health and care needs.
- Engage in training about patients' different communication needs to support improved information sharing.
- Find ways to identify patients' support needs to help staff recognise where adaptations may be required.

3.4.3 Make Accessibility a Priority

Healthcare settings should prioritise ways of supporting patient attendance through an individualised approach. Recommendations for practitioners included:

- Provide patients with clear directions and information in advance of appointments to allow time for planning.
- Prioritise overcoming physical access barriers in the buildings you work in to avoid incomplete screenings and undignified procedures for patients.
- Improve accessibility by providing patients with options that meet their needs.

4. Discussion



The BU PIER Community Researcher Model follows the principle that individuals who are most affected by an area of research should be involved in directing all stages of the research cycle; this involves drawing on their expertise as community members to understand their lived experiences, and to identify problems and their potential solutions (Wang et al., 2017). Under this model, the community researchers were able to connect with people who may otherwise have been unwilling to engage, allowing the creation of meaningful work *with* participants (Hughes & Duffy, 2018; Shore, 2003). The lived experiences of the community researchers allowed open and honest conversations with participants through shared understanding and culture, as well as shared experiences of cancer care (Emerson et al., 2024; Tansley et al., 2024). This was especially exemplified in the Autism Hampshire group as the community researchers were able to navigate the potential anxiety of autistic group members around a change in routine (Beardon, 2021). Feedback from many of the participants across the workshops was one of *finally* being listened to and understood, and, as a result, the data captured was rich and in-depth.

Central to the BU PIER Community Researcher Model is creating safer spaces for participants to share their experiences without judgement. Conversations were at the pace of the participant, and often many things were discussed before talking specifically about cancer care. This allowed time for participants to relax into the process, and for the research team to contextualise participants' experiences within their everyday lives. Sharing these conversations over tea and biscuits allowed for conversations to feel more relaxed, and for participants to feel listened to and valued. Choice and autonomy were also built within the research team. The community researchers were given choices in how and when they wanted to be involved with the project. They preferred to lead in most instances and provided a safe environment for other team members to ask questions and develop a shared understanding of disability. The choice of language and disability frameworks used within the project were directed by the community researchers and in line with participant preferences, i.e., the Neurodiversity framework (Chown, 2021),

The asset-based approach of the BU PIER Community Researcher Model was an effective method to mentor and build the capacity of the community researchers and community partners. As K.J., BU PIER lead, reflected:

Being involved in this process has furthered my understanding of the demands and rewards associated with using the BU PIER Community Researcher Model. It has cemented my confidence in the power of partnership working where relationships are at the heart of the process. This way of working invites and inspires transformative relationships where all involved have the opportunity to see things from new angles and learn and grow together.

K.J. shared how the 'What I would like to say...' project achieved its third aim of further developing the BU PIER Community Researcher Model. This is the first instance in which the model was used when working with people with disabilities, and shows that it can be adapted to support different research aims and populations.

Additionally, the BU PIER Community Researcher Model has been effective for its second aim: to understand and share the cancer service experiences of disabled participants across Wessex. Shared through academic journals which go directly to community nurses (Tansley et al., 2024), shared at several cancer research conferences, as well as at the All Party Parliamentary Group on Cancer (Munday & Tansley, 2023). This has given the community researchers the confidence and ability to lead the second phase of this work (see Munday & Tansley, 2026). Furthermore, at the time of writing, the community researchers are working with two hospitals in Wessex to improve the accessibility, and gender inclusion, of their screening services. This is in conjunction with another research team who used the BU PIER Community Researcher Model on a previous project entitled Trans Aware Cancer Care (Hand et al., 2026). This is evidence of the effectiveness of the BU PIER Community Researcher Model in its first aim: to build capacity within a community for engaging and leading on inclusive



research. Moreover, the aforementioned anxious workshop participant is now a BU PIER member who contributes their lived experience to research conducted at the centre.

The outcomes of this project were further reaching than was anticipated and included the experience gained by community researchers, improvement of the research team's knowledge, breaking down barriers to participation, and creating epistemic communities in which we all learn from one another. The highlight of such work is not only the methodology, but the ability to underpin accessible practice that leads to better diagnosis and treatment for people with disabilities. We have started to apply this both within our own practice as a clinical nurse specialist (A.D.) and as community researchers working closely with two mammography teams to improve the access, and the potential treatment outcomes, of disabled patients in Wessex.

5. Limitations

Despite a diverse range of abilities, disabilities, age and gender, our participant pool lacked ethnic and racial diversity. Future work in this area must include groups and individuals at the racialised and disabled intersection and include community researchers from more diverse cultural and ethnic backgrounds. This should include working alongside Global Majority disability groups such as ADHD Babes, Scottish Ethnic Minority Autistics (SEMA), and Differently Abled Muslims. Similarly, the participants in the current study were already receiving support through their social group. Future research would benefit from engaging with participants who have less access to support groups, including those from more remote areas, as well as those who are vulnerably housed, unhoused, or live nomadically.

6. Conclusion

The BU PIER Community Researcher Model allowed for community researchers to be at the heart of all aspects of this project, which was essential in hearing, understanding, capturing, and amplifying the voices of participants. Focusing on accessibility, an informal and relaxed atmosphere, and enabling participants to feel valued and listened to produced deep findings from the knowledge and lived experiences of all involved (Tansley et al., 2024). The BU PIER Community Researcher Model offers an effective approach for inclusive research with disabled communities and has the potential to inform improvements in asymptomatic screening and primary cancer care. It is important to note however, that what worked for this group of disabled participants and community researchers may not work for others. The crucial elements for future projects are relationships and trust, building this from the point of recruitment and role-modelling within the research team so that it can be seen, felt and heard within workshops.

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Same Food as Self Care: A Community Perspective on Autistic People's Relationships with Same Foods

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Abstract

Autistic people often have strong, enduring preferences for specific 'same foods'. These foods are eaten repeatedly due to sensory, emotional, or practical benefits. While such eating patterns have been discussed in research, they are frequently framed through a deficit lens and rarely centre Autistic perspectives. This article reports on community perspectives revealed during the 'Same Food as Self Care' workshops that were designed and led by Autistic professionals and delivered to Autistic adults in both online and in-person formats. The sessions explored participants' same food experiences through discussion, creative reflection, and self-advocacy activities. Thematic analysis of participant contributions and a post-session survey revealed four key themes: (1) same foods as vital for emotional regulation, stability, and joy; (2) increased community connectedness and reduced isolation through shared experiences; (3) limited access to affirming support and professional understanding regarding Autistic eating patterns; and (4) same foods as a practical and intentional form of self-care. These findings challenge deficit-based interpretations of Autistic eating and highlight the value of same foods as a natural and supportive feature of Autistic life.

For many participants, these workshops represented the first time they had discussed their food experiences as Autistic people. This underscored the importance of creating more opportunities for community exploration of these topics. Furthermore, the Autistic adults were able to discuss together how their same foods meet their nutritional, regulation and overall wellbeing needs. Therefore, when professional input around food and eating is needed, we suggest that practitioners could expand their curiosity on the role that this prevalent community trait may have on individuals. Moreover, as these insights from adults were based on free workshops and not from a formal academic study, we suggest that Autistic people's experiences of food requires future research.

Keywords: Same food, Autistic, Autistic community, Autistic Self-care, Autism and food

1. Introduction

Being Autistic is an all-encompassing experience and way of being (Davies, 2022; Milton, 2017). This means that we bring our ways of thinking, needs and abilities to all activities that we engage in. Additionally, this includes food sourcing, preparation and eating. We therefore have unique behaviours and shared experiences with food that constitute a significant part of Autistic culture

(Frarahar, 2022). Autistic ways of eating can also be a source of expression, joy and belonging (Rose, 2025). The diversity of these experiences are reflected across the Autistic community, as described by many individuals personal accounts (Boren, 2022; Lynch, 2019). One specific and widely recognised example of this is the concept of same food.

When Autistic community members discuss same food, they are often referring to a favourite food that they have a strong emotional connection to (Stephenson et al., 2024). These foods are described as being “staples in a person’s diet, providing a sense of stability and enjoyment, especially for those with sensory sensitivities or a need for routine in their eating habits” (Hellfeld, 2025). Furthermore, to eat and be nourished, feeling safe and regulated is essential (Klein, 2024). When we discuss same foods in this article, we are describing a multi-faceted experience in the Autistic community that serves different functions for each person. These foods may accompany an Autistic person’s meals every day, or they could be snacks or foods solely eaten on their own. Autistic people’s preferences for same foods have been discussed in academic literature over the years; however this has largely been framed through a deficit-lens (Cermak et al., 2010; Mari-Bauset et al., 2014). Additionally, the perspective of the community is rarely considered in publications regarding food and eating.

Moreover, numerous Autistic academics and advocates have pushed for a shift towards neuro-affirming practices in line with the neurodiversity paradigm, which conceptualises autism and other neurodivergences as a natural variation in humanity (Kapp, 2020; Pellicano & den Houting, 2022; Walker, 2021). The ethos of neuro-affirming practice focuses on validating an individual’s subjective experience as opposed to enforcing neuronormative expectations (Dwyer, 2022; McGreevy et al., 2024). Similarly, we believe that adopting this viewpoint towards Autistic people’s relationship with food is also essential. By positioning same food as a natural way of being for Autistic people, this could foster acceptance for this common experience in our community, rather than perceiving it as a deficit that requires fixing.

As two Autistic professionals with our own experiences of same foods, our objective was to ascertain if there was a connection between community member’s same foods and their wellbeing. This inspired us to create the ‘Same Food as Self Care’ workshop at Autscope (2023). Autscope is an Autistic-led conference that offers an affirming space where Autistic people can interact with fellow community members (Belek, 2023). Within this environment, we saw the potential for Autistic adults to feel safe to share and explore their experiences with food through our guided interactive workshop. We later delivered online versions of the workshop through Autistic-led organisations to determine if other adults resonated with the idea of same foods.

This article offers a community perspective on same foods based on the reflections and insights shared from the workshops and a post-session survey following one of the online sessions. Subsequently, we will discuss the implications that these insights could have for professionals, families and Autistic individuals.

2. Methods

We employed a qualitative approach to gather insights from Autistic adults on their experiences of same foods and whether these enhance their wellbeing. This enabled us to explore the subjective accounts of Autistic adults as the heterogeneity of the community means there would be no universal experience of same food. Hence, this resulted in the workshops producing a diverse range of insight and supported participants own construction of their realities of same foods. Furthermore, solidarity and community were central to the workshop delivery by providing participants with a sense of safety to enable them to reflect about and share their same food experiences. We believe that sharing community spaces with Autistic adults would increase this safety for participants. The workshops featured creative exercises and reflective discussions to help elicit adult’s insights. These were designed to offer participants a range of ways to contribute to and reflect on the sessions. Additionally, we developed a post-session survey for one of the online workshops wherein participants provided anonymous feedback. This encouraged further reflections from participants following their involvement in the workshop.

Moreover, we conducted a thematic analysis together by reviewing the written data, such as notes and email feedback from participants, drawings and the survey responses we received to determine the main findings. The analysis was inductive as we wanted to discover themes and patterns of adults’



insights as opposed to drawing on any pre-existing data (Braun & Clarke, 2006). Additionally, given the lack of literature on Autistic adult's perspectives of same foods, this remains an under-explored topic. Thus, this approach allowed us to capture the authentic experiences of participants' relationships with same foods. Details on the workshops delivery and survey are provided further in the article.

2.1 Workshop Settings, Ethical Considerations & Data Collection

It was important that our workshops were exclusive to Autistic adults through events run by Autistic-led organisations. We believed that facilitating these workshops through well-established groups would allow participants to feel safe in attending and sharing their experiences. The workshops were conducted via an in-person session at Autscope in 2023, followed by online Zoom sessions for Autistic Revolution (AR) and Scottish Women's Autism Network (SWAN) in 2024. For the Autscope session, we submitted a proposal to deliver the workshop at the conference, which was subsequently accepted. Our sessions with AR and SWAN featured online meetings beforehand with the organisation leaders, to ensure the content and delivery of the workshop was safe and appropriate for participants.

Online participants were recruited through social media communication via our own pages and the organisations we collaborated with (see appendix for the advert). Thus, participants registered of their own accord. Autscope's programme allowed for people to attend the workshop on the day without prior registration. AR and SWAN featured an Eventbrite booking page for online participants to register. In terms of numbers of participants, our Autscope workshop was attended by 24 adults, while the AR session featured 21 participants and SWAN's session included 42 participants. Moreover, all sessions were free for adults to attend. We only allowed adults to participate due to potential mentions of individuals sharing examples of when eating is challenging. For the SWAN session, this was exclusive to Autistic women and non-binary people, as this is the population that the organisation supports.

None of the sessions were recorded due to the personal stories shared within them. We did not gather personal details of participants such as age or names. Relatedly, any contributions in this article are focused on same food experiences and do not reveal personal identifiers that could compromise participants identity. Equally, our post-session survey for the SWAN cohort did not ask for any personal details, thereby their privacy was protected. The survey results could only be accessed on Microsoft Forms on an account that was protected by a two-factor authentication. We gathered data at Autscope by asking participants if we could take photos of the images, scripts and words they wrote or drew during the group discussion activities. On our last slide, we included our contact information as an invitation for people to send further feedback or reflections and they were informed that we might share these as anonymous contributions in a writeup in the future. Additionally, some participants from the Autscope and AR sessions emailed us their thoughts after the workshops and provided permission for us to use these quotations in a potential article. For the AR online session, we asked participants if we could save their contributions in the chat box and gather these as anonymous contributions for a future article. Further, the SWAN post-session survey provided anonymous written data from participants who expressed interest in sharing their experiences of same food.

Throughout this article we refer to everyone as 'participants' when sharing input from the adults. Furthermore, we asked for consent from all participants across the workshops for us to share any of their contributions or feedback anonymously into an article. This was obtained by asking in advance of the workshops if people were happy for us to share any contributions in a future writeup. This was repeated at the beginning of the workshops, before we facilitated the group discussions and at the end of the sessions when sharing our contact details. The SWAN organisers also made their members aware that completing the survey may lead to their input being featured in an article. Hence, those who responded to the survey offered implied consent for their input to be shared. No participant explicitly objected to giving consent at Autscope to us taking photos of their contributions or when asking to note chat box input at the online sessions. However, some participants chose not to share their insights or written or creative contributions in the group discussions, thus keeping their views private.



2.2 Workshop Design and Delivery

The Same Food as Self Care workshops were designed and led by ourselves. As Autistic trainers, this helped ensure that both content and delivery were aligned with Autistic communication styles, sensory needs and learning preferences. To support predictability, we shared detailed information before each workshop. For online sessions, this included the session structure, participation options, and suggested materials like creative supplies. For the in-person Autscape event, we provided all the necessary resources to support ease of engagement. Participation was always promoted as invitational, never mandatory. Participants could join in through discussion, creative expression, or quiet observation. We encouraged self-regulation throughout, inviting participants to stim, eat, drink, or take breaks as needed. Our aim was to foster a space where people could engage in ways that felt natural and supportive.

All workshops featured a slideshow that we created on Canva to provide some structure and background on the concept of same food, while also allowing for participants to engage in interactive discussions and activities. As the workshop facilitators, we each chose the specific slides that we would deliver to participants. The Autscape session had three to six people at each table and we walked around the room during the discussion and creative activities to interact with participants. For online sessions, we monitored the chat box throughout and provided participants opportunities to share their own perspectives and respond to the prompt questions on the slides. Online participants were able to unmute to contribute while some preferred to showcase their drawings by turning their video on without spoken input. We gave enough time to ensure everyone who wanted to speak or contribute could. The next section outlines the structure of our slides, prompts and activities in the workshops, both for Autscape and the online versions.

2.2.1 Defining "Same Food"

The sessions all began with a brief slide introducing the concept of same food, the tendency of many Autistic people to eat a familiar food repeatedly. To initiate engagement, participants were asked the following prompt question we featured on the slide: "*What other words come to mind when you hear 'same food'?*"

This prompt question was designed to encourage participants to consider their own relationship with same foods. As we introduced this question on the slide, we shared our own experiences, modelling openness and normalising this eating pattern for the participants.

2.2.2 Exploring Personal Experiences with Same Food

Everyone was then invited to reflect on their own same food experiences by considering the prompt on our next slide: "*What is your same food?*"

Participants were then encouraged to look up an image of their same food or to visualise it. Everyone was later invited to share their same food with the group. For in-person, the participants engaged in small table discussions before sharing thoughts with the larger group. The venue at Autscape provided free Wi-Fi for everyone at the conference, thus participants looked up images by searching on their phone if they chose to do so. Online participants were given the opportunity to look up any images on their own devices while we screen shared the slide with the above prompt on the Zoom sessions. They had the option to respond via the chat function or by unmuting their microphones and choosing whether to be on camera or not to share the image they found.

2.2.3 Creative Reflection Activity

To deepen sensory and emotional connections, we introduced a creative segment to the workshop events. Participants were invited to explore the prompt featured on our next slide:

"What colours, shapes, images, emotions or sounds do you associate with your same food?"

Participants had the option to express their reflections through drawing, writing or simply thinking about their responses. Autscape participants were free to interact with each other as they developed their ideas during this activity. For the online events, we recognised the potential of non-interaction leading to participants feeling unsupported or anxious because of the silence. We therefore planned for this creative time to feature music to maintain connection with participants and build an engaging atmosphere. Additionally, this helped to establish the workshop as a positive and enjoyable time.



An Autistic singer-songwriter who goes by the stage name Amity, performed for one online event while for the SWAN session we suggested participants listen to their own music during this activity if they did not feel comfortable in silence. We approached Amity to express interest in him performing as they are Autistic and would potentially relate to the theme of the workshop. Further, an Autistic performer had the potential of helping participants feel safer in a truly Autistic-led space. Additionally, an optional 'show and tell' invitation was extended to participants. Discussions in-person took place at tables before opening to a full-group conversation. The online participants were given time where they could share in the chat, unmute, showcase their creations on camera or engage silently.

2.2.4 Connecting Same Food to Mental Health

Following the creative reflection activity, we introduced the next slide which guided a discussion on the connection between same food and mental health. This segment built upon participant's own insights and responses shared throughout the workshop. By reflecting on the words, images, emotions and sensory experiences that they associated with same food, participants could provide evidence of its role in self-care, regulation and wellbeing.

2.2.5 Self-Advocacy Through Scripts

For our next slide and section, we aimed to empower participants in navigating meal times and social food situations, thus we introduced practical scripts for self-advocacy. The theme of Autscope 2023 was 'Advocacy and Autonomy', therefore these scripts were designed to help Autistic individuals communicate their food preferences and needs in different settings while reducing stress and social pressure. Subsequently, we continued this theme and activity with the online sessions. Moreover, the stigma that Autistic people experience in society may make self-advocating more difficult (Han et al., 2022; Turnock et al., 2022). Relatedly, long-term experiences of masking can add to the challenges in individuals disclosing their needs (Pearson & Rose, 2021). Thus, we provided concrete examples across three common scenarios for this activity:

Self-talk: *"I've had a really stressful day, and I need to eat something familiar."*

At a restaurant: *"Excuse me... Could I please have this without...?"*

Family gatherings or parties: *"I'd like to come, and I'll bring my own food."*

We chose these three scenarios as anecdotally; we often hear in the Autistic community that there is difficulty with self-talk about food needs. Likewise, communicating and expressing needs in public and group settings is challenging for numerous Autistic people (de Marchena et al., 2025; Oldenburg, et al., 2026). Therefore, we hoped this activity would validate individuals' experiences while also providing them the opportunity to create personalised scripts that they could refer to for these situations. Through this, participants were encouraged to reflect on situations where they had felt discomfort around food and think about what they might want to say in those moments. Participants had the option to share their ideas with the group, either through discussions as a group for in-person or using the chat or unmuting to speak during the online sessions.

2.2.6 Capturing Participant Reflections Through Online Survey

Following the session hosted for the SWAN participants, a voluntary online survey through Microsoft Forms was developed to gather feedback and assess how the workshop and discussions about same food resonated with participants. This consisted of seven questions that were designed to verify attendance and collect qualitative insights of participants' experiences, reflections and any potential changes in their perspectives.

3. Results & Main Findings

The following section details the insights (email feedback, Zoom chat messages, script examples, drawings) shared by participants from the workshops, in addition to input from the post-session survey with SWAN participants. Additionally, we outline the main themes resulting from these findings.

3.1 Descriptions and Meanings of Same Foods

Participants at the Autscope and AR sessions shared written notes and chat messages that described their same foods using a range of words that reflected emotional, sensory, and psychological significance. Common descriptors included: 'soothing', 'escapism', 'co-regulation', 'reliability', 'familiarity', 'embrace', 'stability', 'consistency', 'self-care', 'security', 'reassuring', 'respite', 'sanctuary', 'calming', 'ease', 'comforting', 'certainty', 'accommodation' and 'nostalgia'.



3.1.1 Personal Narratives and Food Rituals

Participants shared individual accounts of their same foods and the routines surrounding them during the creative activity:

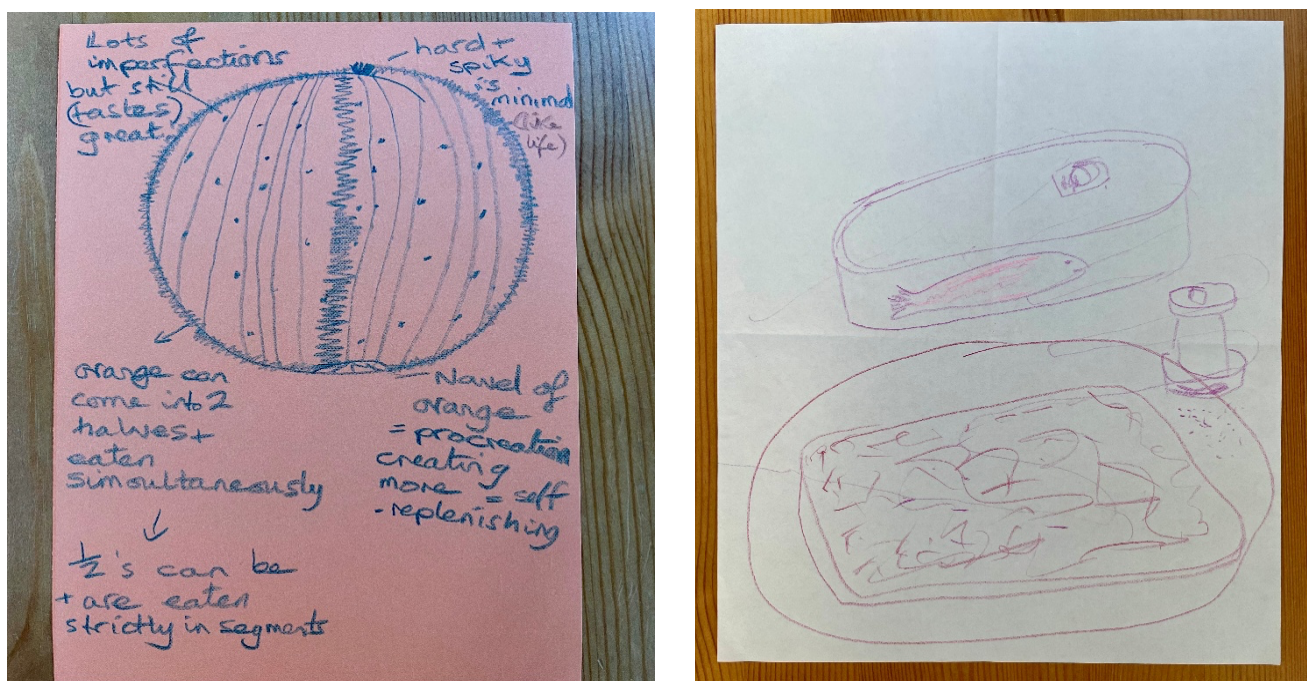
Sardines on Bread: One participant at Autscope reported eating this meal daily for lunch, meticulously preparing it with evenly spread olive oil, evenly spaced sardines, and a sprinkle of pepper. They described it as a vital part of their day, stating, “Life simply wouldn’t have the joy it does without this lunch every day.”

Lentils as a Nutritional and Financial Strategy: Concerned about both health and financial constraints, an Autscope participant adopted lentils as the staple base of most meals. The participant described then adjusting additional ingredients based on availability. This approach allowed them to maintain a consistent dietary foundation while accommodating small variations.

Ferrero Rocher: Another Autscope participant described the multisensory experience of eating Ferrero Rocher, emphasizing the satisfaction derived from unwrapping, consuming the outer layers and reaching the chocolate and the nut at the centre.

Oranges: One Autscope participant shared that they consume oranges daily. They enjoy the precise act of splitting them into equal halves. They expressed distress when the fruit did not separate evenly, emphasising how this detail affected their overall experience. Symbolically, they connected the hard texture of where the stem had separated from the orange to the challenges in life, describing the act of eating as both a ritual and a reflection.

Figure 1: Autscope Participants Drawings of Same Foods



3.1.2 The Role of Same Foods in Health and Wellbeing

One participant at Autscope sent us an email on how they reconsidered their meal-planning approach after the discussion. They expressed that maintaining a rotating variety of dishes had been overwhelming and speculated that narrowing their meal choices to a consistent set of options could ease decision-making and improve their wellbeing. Specifically, they reflected on how they could learn a set of meals to repeat that met their nutritional and medical needs, thereby minimising overwhelm in meal planning and food sourcing.

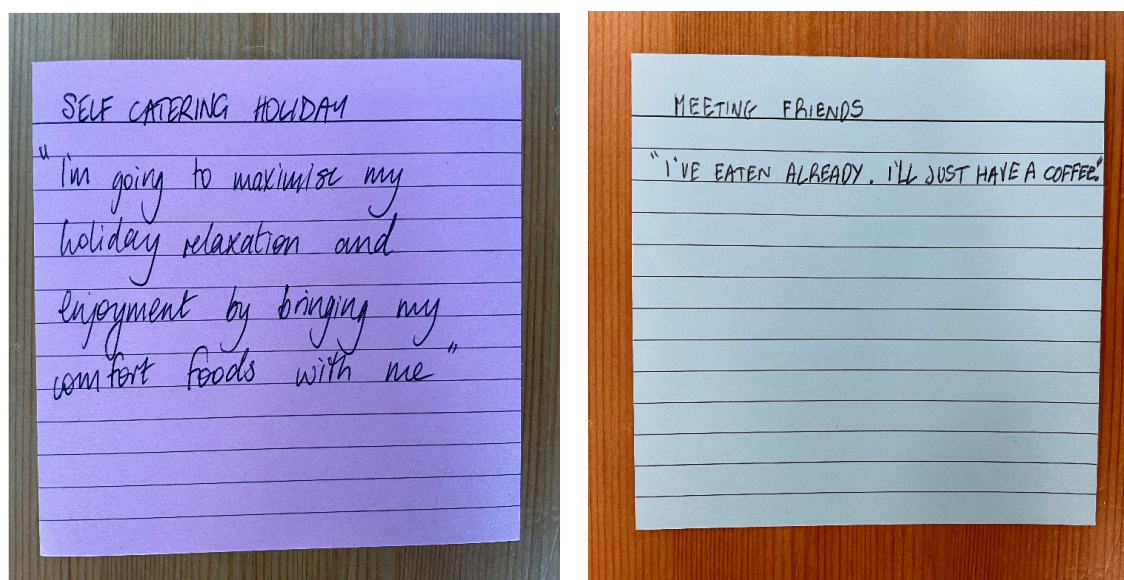


3.2 Participant Scripts and Self-Advocacy

Several participants from the Autscope and AR session shared scripts that they had developed for different food-related situations, showcasing strategies for navigating social and practical eating scenarios:

- Self-catering holiday: *"I'm going to maximise my holiday relaxation and enjoyment by bringing my comfort foods with me."* – Autscope participant
- Hotel stays: *"Can I have more teabags, please? I have run out."* – AR participant
- Restaurant interactions: *"Please can I have it without...?"* and *"What ingredients are in the sauce?"* – Autscope participant
- Self-talk strategies: *"Wait a while between courses and check if you're still hungry."* and *"I am looking forward to my dinner."* – AR participant
- Social dining scenarios: *"I've eaten already, I'll just have a coffee."* – Autscope participant
- Decision-making frameworks for ordering food: One Autscope participant realised that they would benefit from looking at a restaurant menu and deciding on choices ahead of going in-person. They created a potential food order plan with preferred options: Plan A (gammon steak), Plan B (macaroni cheese), and Plan C (mild curry).

Figure 2: Autscope Participants Script Examples



3.3 SWAN Survey Responses

A follow-up survey through Microsoft Forms was shared with SWAN participants to assess their experiences and gather additional insights of their reflections on the workshop. The following section outlines the survey questions and some of the responses we received.

3.3.1 Attendance Confirmation: "Did you attend the workshop 'Same Food as Self Care' with Scott Neilson and Laura Hellfeld?"

Thirteen respondents confirmed having attended the *Same Food as Self Care* workshop with SWAN.

3.3.2 Reasons for Attending: "What reason(s) were you interested in attending 'Same Food as Self Care'?"

We asked this question to understand what brought people to the Same Food as Self-Care workshop. We were interested in whether people attended because the topic was particularly relevant or interesting to them, or simply because they regularly take part in SWAN's monthly offerings, or for another reason. Participants attended for various reasons, including personal relevance, self-discovery and a desire for community:



- "I eat the same foods daily but also have a very limited diet."
- "I'm autistic but also have an eating disorder."
- "Self discovery and to feel ok about who I am."
- "I'm an autistic young adult looking to learn more about same foods, and what that means for me."
- "I thought I had an issue with eating same foods all the time I am glad there are others who do the same."
- "I used to criticize myself for struggling with food. This seminar helped me realize it's okay."
- "I wanted to see if other autistic individuals had similar experiences."
- "Recently diagnosed with autism and have binge eating disorder - I thought this would be a useful session to learn more."

3.3.3 Opportunities for Food Discussions: "Have you had a prior opportunity to gather with other Autistic individuals and discuss food and eating?"

We were curious if participants had any previous opportunities to discuss their food and eating experiences with other Autistic people. Eleven respondents indicated they never had an opportunity to discuss food and eating with other Autistic individuals. One noted: "No never, it's been really great, made me feel much less isolated and realise I am not a difficult or annoying person."

Two participants responded 'yes' that they have had the opportunity and it was either "at a SWAN autism support group with neurodivergent friends" or "an EDAC (The Eating Disorders and Autism Collaborative) research project."

3.3.4 Same Foods Reported: "What is/are your same food(s)?"

The next survey question was to learn about the range of same foods that participants reported. These foods included diet coke, chocolate, fizzy water, roast potatoes, salted pretzels, white bread with butter, chicken nuggets, porridge, crisps, chips, fruit and fibre peach yogurt, banana, chicken salad, salmon, curry, ham sandwich, crackers and cheese, lasagne, garlic bread and potatoes, tuna mayo sandwich on white bread, cheesy pasta, oranges, radishes, boiled sweets, cereal and sandwich thins.

One respondent described preparing the same stir-fry batch weekly with precisely measured ingredients, ensuring consistency.

3.3.5 Associations with Same Foods: "What words or phrases come to mind when you think of your same food?"

To connect with the workshop's aim of reflecting on same foods, we asked respondents what came to mind now when thinking about their same foods. Participants associated their same foods with a range of words and emotions:

- "Safe"
- "Routine, safe"
- "Safe, happy, calming"
- "Comforting and safe"
- "Tasty, safe and happy"
- "Comfort food"
- "Calm, joy, cosy, hugged, relaxed and warm"
- "Safe, convenient, healthy, nurturing and nourishing"
- "Safe, happy, comfort, peaceful"
- "Safety, comfort and routine"
- "Security, stability, routine and calming"

One respondent highlighted: "My morning porridge with chocolate gives me the same feeling I had of being around my grandparents - loved, nurtured, cared for."



3.3.6 Takeaways from the Workshop: “What ideas are you taking with you from the ‘Same Food as Self Care’ workshop?”

Our question was to ascertain if participants learned anything about their experiences of same food or had any changes in their perspectives following participation.

- Many participants expressed relief in discovering that same foods are a shared experience.
- One respondent noted: “That I am not mad!!! There are others like me.”
- “I feel less alone, it’s really nice to know how many people also have same foods. It was lovely to hear the speakers talk about their own experiences with same foods.”
- “That I can eat the same food that I want and there is nothing wrong with it.”
- “I enjoyed hearing about other people’s same foods which made me feel more ‘normal’. My eating habits have always made me feel different so hearing other people’s experiences was really validating.”

Others highlighted the importance of self-acceptance:

- “Just enjoy being me and enjoy the food that makes me feel nice.”
- “That it’s ok to have positive self-talk”
- “It’s ok to be me”
- “That I can eat the same food that I want and there is nothing wrong with it.”
- “It is ok to eat the same foods, I think because I live alone that most people don’t really notice that I eat the same food and when they do (i.e. at lunch or something at work) I am made to feel that it’s not ok.”

3.3.7 Access to Support and Learning: “Do you think Autistic adults receive adequate access to learning about themselves and/or support in regards to food and eating?”

Finally, our last survey question was to understand whether participants felt there was enough access to educational opportunities (particularly from lived experiences) and support about Autistic people’s experiences of food and eating.

The majority of respondents felt that Autistic adults do not receive adequate access to support regarding food and eating. Several pointed out a lack of resources and professional awareness, particularly in healthcare settings. One participant stated: “Definitely not - much more is needed. I am overwhelmed by how much I suddenly need to learn about myself at age 48 and underwhelmed by the resources available.” Another participant stated: “Not at all, I think it would be good to be able to understand better why I eat the way I do and that its part of the lived autistic experience and then it would also be good for society to understand so that we aren’t made to feel ashamed of the way we eat/experience food.”

3.4. Core Themes

After reviewing the various input shared with us from each event and in the post-session survey with SWAN, we identified four themes from the Autistic adults who participated in the workshops. The following section will provide a thematic analysis of their insights based on us exploring the written notes (script examples, chat messages, email feedback), drawings and survey responses that we received.

3.4.1 Emotional Needs/Mental Health

Participant reflections across each workshop consistently linked same foods with mental health. They described them as essential strategies for emotional regulation, self-soothing, and psychological safety. Words like ‘respite’, ‘security’, and ‘sanctuary’ were used to convey their comforting role during stress or overwhelm. Same foods offered stability, predictability, and control in a world that often feels chaotic or overstimulating.

Participants spoke candidly about the emotional relief of having a space to talk openly about food without judgement. One SWAN participant remarked that the workshop “helped me realise it’s okay”



to have consistent eating habits, while another SWAN participant reflected, “It’s helped me start to re-frame some of the self-talk I tell myself” and “it was important to start the process of accepting my choices more confidently”.

Alongside comfort and stability, joy was a prominent theme in how participants described their same foods. One Autscape participant spoke of their daily lunch of sardines on bread as a vital source of happiness, sharing, “Life simply wouldn’t have the joy it does without this lunch every day”. Others at the sessions expressed delight in the sensory experiences of their foods which included the pleasure of unwrapping a treat, the satisfaction of a familiar texture, or the calm of a well-practiced routine.

3.4.2 Community Connectedness

Another core theme in the feedback was the strong sense of community that the sessions fostered. Many participants valued hearing about other Autistic adults’ experiences with same food, with several attending specifically to explore whether others shared similar patterns. One SWAN participant shared in their survey response, “I thought I had an issue with eating same foods all the time, I’m glad there are others who do the same”. Others said the workshop eased feelings of isolation around their food habits. As one SWAN respondent wrote, “It’s been really great, made me feel much less isolated and realise I am not a difficult or annoying person”.

A participant at Autscape emailed us written feedback, “It was so great to hear from other autistic adults on this subject as everything I have seen is about children”. A SWAN participant noted, “I feel less alone, it’s nice to know how many people also have same foods”. One SWAN participant wrote, “That I am not mad!!! There are others like me” highlighting how this commonality helped reframe self-perceptions. Finally, another SWAN participant described this shared understanding as deeply validating: “I enjoyed hearing about other people’s same foods, which made me feel more ‘normal’. My eating habits have always made me feel different, so hearing other people’s experiences was really validating”.

3.4.3 Access to Learning and Support with Food

Most SWAN survey respondents felt that Autistic adults lack adequate support around food and eating. Similarly, many participants during the Autscape and AR sessions highlighted the limited resources and low professional awareness, especially in healthcare, of how Autistic people eat. While two survey respondents mentioned discussing this with SWAN, they noted a lack of similar opportunities elsewhere to explore their experiences.

Across the workshops, many felt professionals need more education on Autistic eating preferences. Several people also stressed the need to centre Autistic voices in these conversations, as they are often excluded from this narrative. One SWAN survey respondent described how current attitudes and policies around Autistic food needs fall short, based on their professional experience:

In my job as an allied health professional, there are so many policies around school dinners which are not ND affirming and which make children's lives difficult at school, it would be great if the powers that be consulted with the autistic community when making these rules so that they could understand that a child who needs different foods not to be touching isn't naughty or difficult just doing what they need to do to feel safe.

3.4.4 Self-Care

Another key theme from participants’ feedback was the link between same foods and self-care. We included this in the workshop title, anticipating that it would prompt reflection on how eating habits may relate to meeting personal needs. Participants frequently mentioned ‘routine’ when discussing same foods, along with words such as ‘stability’ and ‘security’ also appearing in the survey responses. These responses reinforced how the predictable nature of same foods help Autistic adults to maintain balance.

The word ‘accommodation’ also appeared frequently during discussions, highlighting how same foods help people adapt routines to their needs. One SWAN survey respondent described about preparing



the same stir-fry each week with precisely measured ingredients, ensuring consistency. An Autscope participant shared through their drawing how lentils became their prominent food to support their health and financial concerns. A further example came from another Autscope participant who reconsidered their approach to meal planning. They found rotating meals to be overwhelming and planned to shift toward a smaller set of reliable options that met their dietary and medical needs, thereby reducing decision fatigue.

During the activity focused on scripting self-advocacy statements around food needs, one Autscope participant shared: "I'm going to maximise my holiday relaxation and enjoyment by bringing my comfort foods with me", highlighting the importance of same foods during periods of traveling. Another Autscope participant created a personalised framework for ordering at restaurants to mitigate stress. They realised that they would benefit from viewing a restaurant menu ahead of time, developing a plan of several options to prepare for.

4. Discussion

The Same Food as Self Care workshops fostered community connections, validation, and self-acceptance among Autistic adults. Participants engaged deeply, sharing experiences, developing self-advocacy strategies, and reflecting on how same foods can support wellbeing. The overwhelmingly positive feedback underscores the need for continued conversations and resources on Autistic people's relationships with same food.

Workshop participants reported reduced isolation, echoing research that links Autistic community integration to positive wellbeing outcomes (Cage et al., 2022; Watts et al., 2024). Similarly, research suggests that developing a positive Autistic identity has a considerable influence on improving individuals' mental health (Cooper et al., 2021; Davies et al., 2024). Exploring same foods together helped participants view this aspect of their identity more positively, highlighting the value of dedicated Autistic spaces (Botha et al., 2022; Crompton et al., 2022; Milton & Sims, 2016). The word 'routine' was frequently shared by participants. Routines are known for providing stability for many Autistic people (Petty & Cantwell, 2025). Beardon (2017) coined the concept of 'global stability' to describe how life is largely unstable for Autistic people due to systems and services being misaligned with their needs. Therefore, any elements of routine become essential features of their life to achieve some semblance of balance. Same foods emerged as a key part of these routines for our participants, thereby supporting emotional regulation and reducing anxiety.

Many participants shared that meal planning adaptations supported their food needs, particularly in relation to executive functioning (EF) challenges. These challenges are commonly reported within the Autistic community (St. John et al., 2021). EF difficulties such as task switching, planning, and remembering sequences are often exacerbated by stress and sleep issues, which are also frequently experienced by Autistic people (Halstead et al., 2021; Moseley et al., 2021; Tsai et al., 2021; Whelan et al., 2022). In this context, familiar and predictable foods may serve as a necessary accommodation for Autistic people. Our findings suggest that these food preferences can help to reduce the overwhelm of EF related demands, particularly those linked to the many steps involved in typical meal planning, sourcing and preparation.

During the self-advocacy activity, participants shared various scripts and strategies, reinforcing the diversity of approaches that could work depending on individual needs and environments. Promoting self-advocacy is frequently cited as an essential principle of neuro-affirming practice (Edwards et al., 2025; Shear et al., 2025). The co-creation of these advocacy tools served as a practical conclusion to the workshop, equipping participants with tangible strategies that they could apply in real-life situations. In addition, this also reinforced the broader theme of honouring Autistic food preferences as a form of agency.

The workshops also aligned with the double empathy problem (Milton, 2012), which emphasises that Autistic and non-autistic people experience the world in qualitatively different ways. Based on the findings from our workshops, it seems that Autistic relationships with food could be different from how non-autistic people engage with eating. In accordance with the concept of the double empathy problem, we suggest that Autistic eating preferences are not a disorder or deficit, but are instead a natural variation in experiences of food.



Participants demonstrated strong self-awareness and agency around food. This challenges outdated theories that have historically questioned Autistic people's ability to understand their own thoughts or the thoughts of other people (Williams & Happé, 2009; Yergeau, 2018). This highlights how Autistic people may benefit from more opportunities to explore what they need in relation to their food preferences. Therefore, presuming competence, which is frequently highlighted as a key foundation of neuro-affirming practice (Wise, 2023), is critical in our discussion of the narrative about Autistic people and food. This is equally important when interacting with non-speaking Autistic people, who are often presumed to be incompetent and denied opportunities to communicate their needs (Heyworth et al., 2022).

Stress from the unavailability of same foods was a frequent issue that participants shared. Under a medical model lens, this is usually framed as rigidity among Autistic people (Kinnaird et al., 2019). However, when understanding the internal experiences of Autistic adults, it could be suggested that this stress indicates there is an unmet need. Furthermore, this suggests that interventions that withhold preferred foods may have a negative impact on individuals' mental health. This supports a necessary shift towards neuro-affirming models in healthcare (Kapp, 2020; Lerner et al., 2023). Finally, many participants noted a lack of support and widespread misunderstanding from professionals. This mirrors broader findings on societal stigma around Autistic eating (Stephenson et al., 2024), reinforcing the need for education and acceptance of diverse food needs.

5. Limitations of the Workshops

Although the Same Food as Self Care workshop at Autscope was open to all conference attendees and the online sessions were widely advertised, we cannot confirm whether any non-speaking Autistic people participated. This is a key limitation, as non-speaking Autistic individuals face significant barriers to both research and community involvement (Jaswal et al., 2024; Lehenhagen, 2020). We also did not collect demographic data such as age, gender, or ethnicity, limiting our ability to explore how experiences of food and self-care vary. Based on observations, most participants appeared to be white and British, meaning that the responses we received likely do not reflect the full cultural diversity of the Autistic community. Cultural beliefs, practices, and relationships with food vary widely (Nemec, 2020; Sproesser et al., 2022), thus this is an area worthy of exploration.

Furthermore, the online format further restricted access, particularly for learning disabled Autistic individuals who may face digital barriers or require alternative formats and support (Chadwick et al., 2023). Altogether, we had a total number of 87 participants across all the workshops, which is a small reflection of the Autistic community's experiences of same food. Ultimately, our participant groups were relatively homogenous and do not reflect the full range of Autistic experiences. Future work could adopt an intersectional approach, ensuring meaningful inclusion of ethnic minority, lesbian, gay, bisexual, transgender, queer (LGBTQ+), learning disabled, and non-speaking Autistic individuals. Exploring these intersections is vital to understanding how Autistic people may use food as self-care. Lastly, as we are reporting on insights from our workshops and not formally funded research, it would be beneficial for researchers to explore Autistic people's experiences of same food.

6. Conclusion

Overall, our findings from the workshops highlight ways that Autistic adults experience same foods and how these can be essential for their wellbeing. Equally significant was the way that participants connected with one another during the workshops, often for the first time around this topic. Therefore, future work and research could explore how the foods that Autistic people eat may help to support their daily needs and create opportunities for deeper Autistic community involvement.

Additionally, our workshop findings suggest that many Autistic adults are able to identify why they need to eat the foods they do, with several participants detailing emotional and sensory benefits to these choices. This disputes the claims that Autistic people are unreliable narrators in articulating their lived experiences (Gernsbacher & Yergeau, 2019). Hence, it may be useful for researchers and practitioners to generate more curiosity towards Autistic people's choices with foods, rather than assuming that there is no purpose or reasoning behind their preferences. This would also be aligned



with neuro-affirming practice, through honouring how individuals experience food, as opposed to imposing interventions that attempt to modify their behaviour (Zaks, 2025). Therefore, we encourage collaboration between Autistic people and professionals to co-create food and eating care plans that are respectful and person-led.

Ultimately, recognising same foods as a meaningful form of self-care repositions eating as an area where Autistic people can exercise autonomy, regulation, and comfort. This perspective calls for a shift in how support is offered. One that centres respect, listens to and trusts in Autistic people's own understanding of what they need. As our workshop participants showed, food choices are intentional and often deeply supportive. Embracing this understanding is key to building more compassionate and neuro-affirming approaches to care. We hope that this article has provided valuable insight into our community's unique relationship with same foods and the importance of celebrating this shared experience.

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Appendix: Social Media Advert for the Workshops

In this workshop, attendants will explore the Autistic food trait of 'same food'. Same foods are foods that we have a great attachment to, our personal favourites. We may eat these foods every day in order to bring ourselves routine or comfort.

Participants will be welcomed to draw or look up an image of one of their same foods. For those comfortable, we can share these foods and community moment with one another.

We will then explore our emotional and sensory responses to our chosen same food. Participants will be encouraged to draw or write what emotions, colours, shapes, music (or anything else!) that they feel when thinking of their same food.

We will explore how our same foods therefore provide an important piece to our mental well-being and self-care. Participants will then be guided to create scripts for themselves to help navigate social eating scenarios and advocate their food needs.



Original Research Paper

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Dismissed as just a “chatterbox”: Examining Childhood Symptomatology, Educational Costs and the Effects on Mental Health of Delayed Diagnosis of ADHD in Women

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Abstract

The diagnostic criteria for ADHD were historically constructed on male, cis gender, presentations that make female symptoms atypical in comparison. This has contributed to a poor understanding of female presentations of ADHD and underpins the diagnostic gender gap varying from 2:1 to 16:1 in childhood.

Semi-structured interviews with ten late-diagnosed women, aged 25-64 ($M = 41.70$; $SD = 11.26$), were conducted. Using Interpretative Phenomenological Analysis, this study examined the lived experiences of women diagnosed with ADHD in adulthood to retrospectively explore childhood symptomatic ADHD behaviours and how gender influenced delayed diagnosis. Findings indicated participants exhibited symptoms from early childhood and struggled with feelings of otherness and shame. Hyperactive tendencies were reported as objectionable in females from an early age leading to concealment and internalisation of perceived flaws.

Adolescence was marked by mounting scholastic difficulties, low self-esteem and poor mental health. Participants remembered suffering from overwhelm, rumination and incessant mental activity as well as a structural inability to sustain attention and maintain composure; symptoms highly indicative of ADHD but missed. ADHD medication, post-diagnosis, brought mental clarity and focus. Future research should investigate female specific indicators of ADHD and how hormonal fluctuations escalate symptoms.

Keywords: ADHD, Gender Bias, Female Symptomatology, Delayed Diagnosis, Consequences

Data availability statement: The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions

Introduction

Female health remains underrepresented in medical research (Academy of Medical Sciences, 2021). Historically, clinical trials have relied on cis-male samples, embedding male-centric symptom profiles into diagnostic frameworks that have created persistent data and knowledge gaps and health systems that disadvantage women and girls (Alvaro, 2025; Allegra et al., 2023; Patalay & Demkowicz, 2023; Shansky & Murphy, 2021). These structural biases are particularly evident in the under- and misdiagnosis of attention deficit hyperactivity disorder (ADHD) in females.

ADHD is a prevalent, lifelong neurodivergence characterised by difficulties with inattention, hyperactivity and/or impulsivity and associated with dysregulated dopamine and norepinephrine transmission (Eng et al., 2023; Hinshaw et al., 2021; Metha et al., 2019; Nigg et al., 2020). The *Diagnostic and Statistical Manual for Mental Disorders*, 5th ed. ([DSM-5] American Psychiatric Association [APA], 2013), groups ADHD in three core categories, (1) predominantly hyperactive/impulsive, ADHD-H/I; (2) predominantly inattentive, ADHD-I and (3) combined ADHD, ADHD-C. Although ADHD generally represents the same biological syndrome across sexes, diagnostic ratios before age 18 range from 2:1 to 16:1 in favour of males (Martin et al., 2024; Quinn & Madhoo, 2014; Walters, 2018; Williamson & Johnston, 2015; Young et al., 2020), indicating substantial gender bias in identification rather than true prevalence differences.

A key contributor to the systemic underdiagnosis of girls is the reliance on the male-centric diagnostic criteria of the DSM-5 (APA, 2013). These criteria are largely derived from research containing samples of elementary school-aged boys and highlight overt hyperactive and impulsive behaviours which are less likely to be expressed or expressed differently by girls (Hinshaw et al., 2022; Mowlem et al., 2019; Murray et al., 2018). Girls tend to experience symptomatology later, particularly during puberty, and rarely display problematic or disruptive classroom behaviours that prompt referral (Ayano et al., 2023; Eng et al., 2023; Nigg et al., 2020). As a result, parents and teachers frequently overlook ADHD in girls or misattribute symptoms to personality traits or hormonal changes (Klefsjö et al., 2020; Lynch & Davison, 2022; Meyer et al., 2020; Patalay & Demkowicz, 2023).

Diagnosis is further impeded by the widespread assumption that girls suffer overwhelmingly from inattentive ADHD and do not present with hyperactivity/impulsivity. Clinical research however does not support greater inattentiveness in girls than boys (Ayano et al., 2023), nor the absence of hyperactivity or impulsivity when female symptomatology is appropriately contextualised (Waschbusch & King, 2006). Female symptomatology of hyperactivity/impulsivity, such as interrupting and talking over others, taking things a bit too far, being too loud, or generally being “too much” (Morgan, 2023; Walters, 2018) violate gender norms (Glaser-Holthe & Langvik, 2017; Loyer-Carbonneau et al., 2021; Morgan, 2023) and are often heavily sanctioned, especially by same sex peers (Attoe & Climie, 2023; Blum et al., 2017; Kok et al., 2016). Girls quickly learn to suppress and internalise their hyperactive impulses to maintain normalcy, often at great expense to themselves (Nussbaum, 2012; Young et al., 2020). Externalising ADHD behaviours are undesirable in society across genders (Beaton et al., 2020), but this is magnified for girls. Female hyperactive tendencies must present within the strict bounds of gender mandates for feminine behaviours such as, pleasing others, being prosocial, cohesive and compliant (Blum et al., 2017; Patalay & Demkowicz, 2023; Vinagre-González et al., 2020; Williamson & Johnston, 2015). Lacking gender compliant opportunities to express ADHD-associated restlessness, ADHD in girls frequently manifests in emotion dysregulation/hyperactivity (De Ronda et al., 2024), rumination and racing thoughts (Lynch & Davison, 2022).

Missed or delayed diagnosis of ADHD in girls is associated with enduring adverse outcomes including chronic low self-esteem (Beaton et al., 2020; Çelebi & Unal, 2021), academic underachievement (Birchwood & Daily, 2012; Koirala et al., 2024), problematic peer functioning (Kok et al., 2016), recurrent somatic complaints, such as head- and stomach aches (Bozhilova et al., 2018; Young et al., 2020) and an elevated risk of developing comorbid conditions, notably anxiety and depression (Martin et al., 2024; Sarwar & Vitetta, 2024), making a timely ADHD diagnosis for girls a critical public health concern.

Although a growing body of literature acknowledges systemic gender bias in ADHD diagnosis (Attoe & Climie, 2023; Glaser-Holthe & Langvik, 2017; Lynch & Davison, 2022; Morgan, 2023), female presentations remain insufficiently recognised. This study aims to advance understanding of how



ADHD-related hyperactivity and restlessness manifest in girls and how parents, educators and primary care clinicians can better identify ADHD in female populations. Using a qualitative design, semi-structured interviews with late-diagnosed women with ADHD were conducted to explore childhood symptomatology, gendered misrecognition and compensatory coping strategies.

Research Question 1: What symptoms were present in childhood? Are female symptoms not recognised and what was the perceived role of gender in delayed diagnosis?

Research Question 2: What coping and compensatory behaviours were used in childhood and how did this affect them?

Method

Design

Interpretative Phenomenological Analysis (IPA) was used to gather data from late-identified women with ADHD about their subjective experiences and retrospections of ADHD in childhood. Primary, person-centred accounts of late-diagnosed women with ADHD were captured verbatim through semi-structured interviews, guided by an Interview Schedule (Appendix A) (Tong et al., 2007).

Ethical approval for this study, based on a full review submission, was granted (#2024-205) by the Ethics Committee of the University of Portsmouth.

Participants

A homogenous, purposeful sampling method was deployed to recruit participants. The study was advertised in various female-only WhatsApp groups inviting late diagnosed women with ADHD, aged 18 or over, with access to a computer, good command of the English language and the ability to provide consent, to contact the researcher. Participants consisted of 10 ($n = 10$) women, aged 25 to 64. Participants completed a survey to gather basic demographic and psychiatric data and to obtain consent. Participants were purposely not asked about their category of ADHD as not to frame their answers or create bias for the researchers. See Table 1.

Table 1

Participant baseline demographic and psychiatric data ($N = 10$)

	<i>M (SD)</i>	<i>N</i>
Age	41.70 (11.26)	
Age of diagnosis	35.20 (10.46)	
Employed		7
Not employed/ homemaker		3
Married/relationship		6
Single		4
Diagnosis before ADHD assessment total		<u>7</u>
- Anxiety		5
- Depression		2
ADHD medication		9
Currently in psychotherapy		5
Resident in the Netherlands		6
Resident in the UK		4
Identified as white		10

Materials

Other than collecting basic data, the online survey presented participants with a 17-item, multiple-choice, ADHD symptom checklist (Appendix B) derived from both the diagnostic criteria of the DSM-5 and existing literature on the presentation of ADHD in females with a focus on racing thoughts and



emotion dysregulation (De Ronda et al., 2024; Lynch & Davison, 2020). Participants were asked to choose descriptions of ADHD symptoms applicable to them in childhood and adolescence, ranging from inattentive symptoms “forgetful-dreamy-scatty/ being accused of being lazy” to hyperactive symptoms “being told to calm down/being on an emotional rollercoaster”. This list included two common ADHD coping mechanisms, such as following a “strict daily schedule and/or being excessively organised”. There was an option to answer with “prefer not to say”. The results of the survey are presented in Table 2.

Table 2

ADHD symptoms as self-indicated by participants (N = 10) in the pre interview survey

Symptoms	Type	% survey
Scatty, dreamy, forgetful	Inattentive	60%
Feeling overwhelmed	Inattentive	60%
Being told off by parents/teachers	Combined	70%
Accused of being lazy	Inattentive	70%
Feeling misunderstood	Combined	100%
Feeling different	Combined	100%
Talkative	Hyperactive	60%
Racing thoughts	Hyperactive	80%
Being on an emotional rollercoaster	Hyperactive	60%
Having a mind like a bolting horse	Hyperactive	40%
Being impulsive	Hyperactive	80%
Trouble sleeping	Hyperactive	70%
Told to ‘calm down’	Hyperactive	40%
Always busy with something	Hyperactive	70%
Following a strict daily schedule	Coping response	<1%
Being excessively organised	Coping response	<1%

Interview Procedure

Interviews were conducted via Zoom and lasted from 45 to 133 minutes. Each interview started with describing the research objectives and confidentiality, before commencing the interview schedule. The researcher kept notes of all interviews and wrote a short reflection after each interview on topics and emotions that were initially notable.

Procedure for Data Analysis and Interpretation

The analysis of the raw interview data followed a 6-step analysis. Participant accounts were transcribed verbatim (1) from the audio and video recordings and, where necessary, directly translated from Dutch into English. Transcripts were (2) then re-read multiple times and checked for accuracy against the recordings, before (3) being analysed inductively and ideographically and summarised into descriptive notes, highlighting relevant verbatim quotes and grouping these around the broader research questions. The notes and isolated quotes were subsequently (4) submitted to a deductive analysis and expanded linguistically and conceptually, allowing for repeating ideas and experiential themes to emerge before being clustered and categorised to identify themes and codes (5) in each individual account separately. Lastly (6), the notes were read holistically across all ten summarised accounts, looking for thematic communalities and differences in participants’ experiences. IPA analysis of the ten interviews revealed 42 thematic codes, which were finally grouped into 3 overlapping super-ordinate themes and 5 sub-ordinate themes based on co-occurrence and common meaning. Participants’ identities were replaced by pseudonyms. See Table 3.



Table 3

Themes from semi-structured interviews with (N = 10) late diagnosed women with ADHD

Superordinate Themes (3)	Subordinate Themes (5)
The Gender Paradigm	Missed Childhood Diagnosis Despite Obvious Symptoms
Otherness	Compliance with Gender Expectations: Early Years
Getting Stuck in Adolescence	Compensating and Coping
	Scholastic Consequences
	Missed Opportunities

Analysis and Discussion

The Gender Paradigm

Missed Childhood Diagnosis Despite Obvious Symptoms

Participants shared hyperactive and impulsive symptomatology from childhood and demonstrated various levels of externalised hyperactivity/impulsivity throughout the interviews (despite having been diagnosed with ‘inattentive’ ADHD). All participants recalled being reprimanded “all the time” for what they now understood to be manifestations of ADHD and being recipients of constant criticism for being “too much”, “too loud”, “too excitable” or for “coming across as bored in conversations”, for talking over- and interrupting others.

“I was dismissed as just a ‘chatterbox’, as if talking a lot is not a symptom of ADHD, ‘oh no, she just talks a lot” (Mila).

“My entire childhood I have been told that I was too much, too hyper, and I was punished for talking back, not sitting still, never finishing anything” (Chris).

“I was often, if not always, told to ‘calm down’ as a child. I was told to be ‘normal’ both at home and at school; told to sit down, to calm down. I felt that my behaviours were undesirable, and certainly for a girl” (Mila).

“You are often rejected, because you interrupt people, you talk too much, you blurt... or because you find it hard to stay focused in a conversation. And when you don’t conform, because you find it very difficult to conform, there are consequences, it is the social punishment” (Amalia).

Compliance with Gender Expectations: Early Years

Participants mentioned noticing gender behavioural expectations first in elementary school, illustrating how gender norms shape girls’ behaviour from a young age (Blum et al., 2017). At school, participants were discouraged from seeking attention - labelled “drama queens” if they did - and expected to be quiet and obedient (Hinshaw et al., 2022). Most women reported generally behaving well at school, certainly better than their male peers (Bozhilova et al., 2018; Waschbusch & King, 2006) and described covertly managing restlessness during lessons through doodling, hair-twirling, frequent bathroom breaks, tapping feet, or mentally “switching off”.

“Girls are expected to sit still and behave well at school. Any other type of behaviour is disapproved of. I could never sit still at school but tried very hard.... I often asked to go to the toilet, just to stretch my legs and I would rock in my chair. There are different expectations for



girls, and we must adapt to that. Girls are judged on feminine qualities. A bit by everyone, but especially at school" (Dora).

"I had restless leg syndrome.....I remember shaking my leg all the time during my school years... I still believe I have the hip pain that I have right now... I still believe it is because of that" (Francesca).

Otherness

Compensating and Coping

Undiagnosed ADHD in females often lead to mental health challenges due to feelings of otherness and not fitting in with neurotypical peers (Morgan, 2023; Walters, 2018). Participants indeed recalled feeling different and misunderstood as children as their perceived character "flaws" were a cause for frequent parental- and peer criticism, leading to feelings of shame and low self-esteem (Attoe & Climie, 2023; Beaton et al, 2020; Kok et al., 2016).

"I was always scared and stressed as a child because I did things wrong, and I just wanted to do them right. I think my cortisol levels were always high as I wanted to be a good child, and I tried really hard. I had to concentrate very hard to do small things right; like not leaving a mess, to be on time and to not be distracted by so many things" (Sarah.)

"I felt I was wrong... that something was wrong with me. Missing something that others had. It really affected my self-esteem, as if what I was, was not allowed. I was not allowed to be different. I was not normal. It summarises my childhood, that I am not normal" (Mila).

Masking, a known compensatory strategy to conceal ADHD symptoms (Morgan, 2023; Quinn & Madhoo, 2014), became routine for participants as they believed that others disliked their authentic selves, making them "outsiders" in their own worlds. Masking was described as exhausting, as "ADHD chaos turning inwards", and a cause for "racing thoughts" and overwhelm (Lynch & Davison, 2022). Half of the participants were diagnosed with an anxiety condition many years before receiving an ADHD diagnosis, illustrating how internalised ADHD in females is frequently missed, misdiagnosed (Klefsjö et al., 2021; Martin et al., 2024; Patalay & Demkowicz, 2023) or not diagnosed as co-occurring (Michellini et al., 2015; Sarwar & Vitteta, 2024).

"Masking doesn't feel right, as if I don't fit, as if I am not good enough. It is exhausting. But if I don't, people say I am too much, too dominant, but I don't mean it" (Dora).

"I had to learn to mask just to get by. Going to school made me physically sick in the morning. I felt nauseous with anxiety because I knew I had to mask and control all of these things. And I punished myself for social transgressions and making mistakes" (Amalia).

"I always had these racing thoughts and many thoughts at the same time. I can't stop my mind. I get overwhelmed by my own thoughts. I am always 'on' and I can't stop" (Mila).

Getting Stuck in Adolescence

Scholastic Consequences

ADHD symptoms in girls often intensify during puberty, when oestradiol's effects on dopamine coincide with rising gender expectations and academic demands (Nigg et al., 2020; Nussbaum, 2012). Entering adolescence with undiagnosed ADHD can significantly impair scholastic outcomes and participants indeed reported encountering increasing difficulties in secondary school, including problems with attention, focus, memorisation, organisation, and completing exams on time. Chronic lateness was common, and many described uneven academic performance, excelling in some subjects while failing others, a performance described as "Marmite".



"School was a patch job: I did everything last minute because I could not remember things for long. I would cram for tests the night before, do the exam the next day and then forget. School was a struggle, like slow death" (Chris).

Participants felt punished for difficulties they did not know how to resolve and were demoralised by teachers and parents who labelled them "lazy" or "unmotivated" for not finishing tasks, leaving them feeling "stupid" or treated as such at school.

"All my school reports said 'shame', you know, 'she has such potential, such a shame she never finishes her exams and never gets her prep in on time', I mean I did get my prep in on time, but then life gets more complicated, and the work get more complicated and it takes longer to do it, and I can't do it..." (Agnes).

"My teacher said I was not making an effort. But is not that I didn't do my best, it is just that my effort wasn't fruitful. I would try to memorise. But I'm not able to focus. No focus. There is nothing I can do" (Francesca).

School experiences were described as negative, with participants often "spending more time outside the classroom than in it" and frequent detentions were common (Young et al., 2020). One participant described school as a "repellent" and refused to attend altogether. Disruptive behaviour was not intentional but recalled as a compensatory response to difficulties sustaining focus, a core DSM-5 indicator of ADHD.

"I was always messing around in the classroom, but this was because I was frustrated about being unable to pay attention. Not to be able to do it" (Sophie).

Missed Opportunities

All participants completed secondary school, although narrowly and with intensive parental oversight, yet collectively lost ten school years. This underscores the academic impact of undiagnosed and unmedicated ADHD (Johnson et al., 2021).

"I mean, I still have nightmares about these awful finals, um, and that stopped me, you know, I intended to go and read Law or something, but my inability to memorise stuff or to do the exams... and I just said, I can't be doing something that is going to require me to take endless more exams." (Agnes).

Earlier diagnosis affords boys timely access to ADHD support and medication, positioning girls with undiagnosed ADHD at a structural disadvantage. Participants' accounts suggest that delayed identification not only constrained academic attainment but also shaped long-term decision-making and life trajectories. Retrospective regret centred on missed potential, with post-diagnosis medication, used by most participants, described as restoring cognitive calm and clarity, combating the abundance of intrusive thoughts. These findings highlight medication as a critical moderating factor (Johnson et al. 2021) in mitigating the cumulative educational and psychological costs of undiagnosed ADHD.

And...before it vanishes because I, I never, I don't remember, you know, I'm constantly having flashes of brilliant thought and then I, which, you know, if I don't write it down there and then, or say it, you know, it vanishes.....never to return." (Agnes)

Limitations

A limitation of this study was the homogeneity of the sample group, consisting of white cisgender females only. Despite the wide age range (24-64) of participants, all had comparable childhood experiences. This is likely different for women from different ethnic groups, who in health-matters often face racial bias in addition to gender bias. The potential effect of the difference between cis and



non-cis females on delayed diagnosis of ADHD was outside the scope of the study. More research is needed to study the role of biological sex, gender-identification and ethnicity on the underdiagnosis of women with ADHD.

Although many participants mentioned how hormonal effects plagued their ADHD symptom severity, from worsening symptoms during the luteal phase of the menstrual cycle, around pregnancy and in perimenopause and menopause, there is limited research on how oestrogen interacts with neurotransmitters, specifically dopamine. This is an important research direction as hormonal influences were reported as also interfering with the otherwise positive effects of ADHD medication.

Conclusion

This study investigated the reasons for delayed diagnosis of ADHD in females, focusing on whether hyperactivity and impulsivity are absent or expressed in gender-appropriate ways, and how coping mechanisms develop and influence outcomes. Retrospective interviews were conducted with ten women diagnosed later in life ($N=10$) to explore experiences of ADHD in childhood. Findings showed that ADHD in girls often goes unnoticed despite the presence of clear symptoms. Participants described hyperactivity and impulsivity from an early age, although these behaviours were frequently criticised by parents and rejected by peers. Such responses contributed to feelings of otherness, loneliness, and shame, and encouraged the development of maladaptive coping strategies. Many participants reported high levels of anxiety during adolescence and early adulthood, and several received anxiety diagnoses prior to recognition of ADHD. Educational experiences were largely negative. Persistent difficulties with attention, organisation, and task completion resulted in frequent reprimands from teachers and parents, who often interpreted these struggles as laziness or lack of motivation. Although all participants completed formal schooling, many did so narrowly, and collectively lost ten school years. In adulthood, participants expressed regret over missed opportunities and unrealised academic potential, particularly when reflecting on the later positive effects of ADHD medication aiding clarity of thought and daily functioning. Overall, the study demonstrates the significant impact of undetected ADHD on the wellbeing, trajectories, and life-outcomes of females, highlighting the need for earlier recognition and gender-sensitive assessment within educational and clinical settings.

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Appendix A

Interview Schedule

4. How are gender stereotypes perpetuated by diagnostic constructs?

- What age were you diagnosed?
- Why did you seek diagnosis?
- How did you feel once you were diagnosed?
- Did you experience symptoms of hyperactivity? What were they?
- What support have you received – medication and/or counselling.
- Did this help with your daily functioning?

5. What socio-adaptive behaviours were/are used to compensate for and camouflage ADHD symptoms?

- Looking back at your younger self - with what you know now - what symptoms were present? From what age? Do you think your symptoms were obvious?
- Why do you think your symptoms were not recognised as ADHD at school or at home?
- Girls and women with ADHD often mask ADHD symptoms well. Did you develop coping mechanisms to cover or manage your symptoms? What were they?
- Do you think gender norms played into how you dealt / coped with ADHD symptoms? How?
- Do you feel you could be you 'ADHD' self?

6. Are anxiety-disorders a result of undiagnosed ADHD / misdiagnosed ADHD?

- Did coping with ADHD without a diagnosis and support cause you anxiety or stress?
- What situations created symptom spikes?
- Were you diagnosed with an anxiety disorder?



- What effect did this (mis) diagnosis have on you and how do you feel about this now that you know it is ADHD?

Appendix B

17 item list of ADHD Symptoms

Looking back on your childhood and your adolescent self, which of the following descriptions applied to you?

ADHD symptoms		Coping responses
<u>Inattentive</u>	<u>Hyperactive/impulsive</u>	
Scatty, dreamy, forgetful	Talkative	Being excessively organised
Feeling different from peers ^a	Racing thoughts	Following a strict daily
Being told off by parents and teachers	Being on an emotional rollercoaster	schedule
Feeling overwhelmed	Mind like a bolting horse	
Being accused of being lazy	Trouble sleeping	
Feeling misunderstood	Being impulsive	
Often late	Being told to calm down	
	Always busy with something	

^a feeling different and feeling misunderstood are strongly associated with ADHD in general.



NeuroconVerse

I always felt I belonged with the world of Neurospicy
My inability to understand why my response was seen as
dicey

The other girls found it easy to fit in and make friends
My time was spent overthinking and making amends

I saw the world literally and my quirkiness pushed me to
the fringe

Under the table with hands on my ears made others
cringe

The world is not patient and wants us to fit and change
Secretly , do they think we're weird and find us strange?

So I became a mimic and mime to learn the ways of the
neurotypical

Pushed down the anxiety and became more cynical
Removed the mask at home and sobbed in my room
Burnt out from the facade and waited for another day to
loom

Eventually it was school saw the bags under my eyes
Carrying the weight of perfection and social lies
The waiting list was long and I felt like I wasted years
But now I understood why and began to allay my fears

S O'Brien (2026)







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