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The meaning of autistic movements

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Abstract

Movement of the body is an essential way to characterise autism, according to diagnostic criteria. However, qualifying descriptions of what autistic movements are, their functions and personal value, are missing from academic literature and clinical guidance. We systematically searched for autistic adults' descriptions of their body and its movement within autobiographical narratives in blog data. Descriptions from 23 autistic authors formed a qualitative data set. The search strategy identified descriptions of movements and meanings without a priori definitions, such as being stereotyped or ritualistic, which were submitted to a thematic analysis. Authors described stigmatisation of some of their movements, causing censorship. However, movement provided personal benefits, including enhanced thinking and focus, routine, sensory regulation, release of energy, increased body connection and awareness, regulated emotion, and time without self-restraint. Examples included stimming or self-stimulating behaviour, dancing, and physical exercise. Movement was accompanied by qualifying descriptions of being natural and harmless. Moving freely, expressively, and sometimes repetitively, strengthened self-identity. In conclusion, body movements have both stigmatised and non-stigmatised appearances for autistic adults, but these cannot be distinguished by the function of the movement. Expressive, regulating and repetitive movements can be a well-being resource for autistic people. Implications for practice are discussed.

Lay abstract

What is already known?

Moving the body in 'stereotyped', 'repetitive', 'ritualised' or 'unusual' ways is part of the criteria for receiving a diagnosis of autism. However, the reasons for these movements and their personal value are not well understood. Certain ways of moving have become part of a disorder, and have received negative judgements, whereas other movements have not.

What this paper adds?

We searched online blogs for descriptions of movement written by autistic adults, using their preferred language and definitions. The blog authors said that many types of movement attracted negative judgement, including mis-coordination shown during sports, dancing in unusual places or moving repetitively, such as when stimming. However, movement provided personal benefits, and could enhance thinking and focus, provide meaningful routine, contribute to sensory regulation, release energy, increase body awareness, emotion regulation and strengthen self-identity.

Implications for practice and policy

Movement could be a well-being resource, used to reduce distraction, overwhelm, confusion and distress for autistic people. This should be considered within personal coping strategies and psychological therapies. The examples provided in this study could inform autism assessments, to ensure that the meanings of movements are considered alongside the appearances of movement. Some movements such as stimming have the same functions as many other ways of moving, including dancing and exercising, which could help to reduce stigma around being autistic if reflected in policy and practice. Improving understanding is important for informing how autism is assessed, and how personal experiences of being autistic are heard.

Keywords

autism, exercise, identity, movement, sensory, stimming, well-being

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The ways in which autistic people move their bodies are predominantly understood through a stigmatised lens, where movements are stereotyped, repetitive, ritualised or unusual behaviours (American Psychiatric Association, 2013). However, this narrow viewpoint is over simplistic; it omits the complex interplay of how a person's behaviour reflects their fit within their environment (Chapman et al., 2022), how behaviours can be modified as a person navigates their identity (Harmens et al., 2022), and the value judgements that they attract because of comparison against how the 'neurotypical' majority behaves (Petty et al., 2023). The criteria for when movement is 'autistic' is unclear, for autistic individuals, their families, clinicians, researchers and those who work with them. The absence of a complex and multi-authored understanding of the many ways in which the body moves, and the reasons why, is contributing to a limited view of what it means to be autistic. A helpful comparison can be made with how experiences of masking or camouflaging (Miller et al., 2021) or sensory fatigue (Smith & Sharp, 2013), are being explored from the perspectives of autistic people. The wider significance of this work is that aspects of behaviour that reflect neurodiversity, or individual differences or strengths, are being disentangled from negative value judgements (Hamilton & Petty, 2023).

The imperative to better-understand movement and its meanings for autistic people is driven by the complicated cooccurrence of differences in sensory processing, interoception and the recognition of body sensations and emotions with autism (Brewer et al., 2015), which need better understanding and accompanying well-being interventions.

Stimming is one type of movement associated with being autistic that has an evolving understanding. The value of repetitive, rhythmic movements or vocalisations, which are sometimes involuntary, can be for self-regulation of discomfort, emotion, sensory overload or noisy thoughts (Kapp et al., 2019). Importantly, though, movement of the body extends beyond stimming. Interviews with five autistic adults have informed a model of body organisation, whereby perception, posture and aspects of controlling, executing and combining movements are suggested to be interconnected (Robledo et al., 2012). Therefore, there is more to be understood about the continuous and routine experiences of the body moving, and the wider impacts on functioning and well-being for autistic people. Jachyra et al. (2020) used digital stories to explore the role of physical activity for 10 male, autistic adolescents. For some, physical activity was associated with bullying and exclusion, when they were perceived to be less physically skilled. Physical activity could also provide opportunity to be free from self-restraint and camouflaging, could promote positive emotions, self-identity and belonging. Wider literature has suggested positive impacts of movement-based interventions for autistic people, including physical exercise and dance (DeJesus et al., 2020; Sorensen & Zarrett, 2014), with improved cardiovascular health and strength, body awareness, self-expression, and non-verbal communication. From this limited research, personal accounts by autistic people have suggested that there are under-recognised functions of movement.

This study explores the meaning of movement for autistic people, first by seeking qualitative descriptions that extend beyond repetitive or ritualistic movements, or formal well-being interventions, and second, by exploring movement as it is embedded within the day-to-day lives of autistic adults, from naturalistic blog data.

Methods

Blog data were systematically searched to create a qualitative dataset of movement descriptions authored by autistic adults. Blogs are online written entries on a topic chosen by the author, usually autobiographical, written to inform and educate others (Gillespie-Lynch et al., 2014). Blogs can provide research data from people who are otherwise difficult to hear from (Wilson et al., 2015). This design also sought to minimise the influence of a priori assumptions and researcher influence over how autism is understood by finding extant data, and sought to hear preferred language, understandings and meanings from autistic people (Kim & Bottema-Beutel, 2019; Pellicano & den Houting, 2022).

Data collection

Blogs were identified following a search protocol (Petticrew & Roberts, 2008) and with close reading of guidance for conducting Internet-mediated research (British Psychological Society, 2021a) and prior blog research (Harmens et al., 2022). Host sites including the National Autistic Society, Actually Autistic and Autistica, Google search and snowballing were used to locate blogs that were written from a first-person perspective, by an author over the age of 18 who identified as being autistic (this included authors who were either formally diagnosed or who self-identified as being autistic), and were accessible in the public domain without requiring password or membership. All demographic information was visible in the authors' blog profiles. Seventy-five blogs were screened for relevance to the research question. Forty-four search terms (Table 1), developed with reference to previous literature, thesaurus searching and reading of 10% of the blogs in full, were applied to identify all descriptions of movement and the accompanying context. A second, independent researcher repeated the process of searching and extracting data to ensure that the authors' perspectives were preserved. A total of 23 authors contributed a dataset of 32 blogs, summing 4742 words. Blog authors were female ($n=14$), male ($n=5$) and non-binary ($n=1$); three authors did not give their gender. Two authors identified as non-speaking.

Table 1. Search terms applied to blog data to locate descriptions of movement.

Search terms
aerobic, activit, athlete, avoid, balance, bod, cycl, danc, energy, exercise, exhaust, express, fatigue, fit, flexib, gym, intens, jog, kinaesthe, meltdown, motor, mov, music, overwhelm, pain, pattern, physical, proprio, relie, repeat, repetiti, restrict, rhythm, run, sens, sport, stim, stretch, swim, temperature, train, walk, workout, yoga

Table 2. Themes of description and the meanings of body movement as described by autistic adults.

Themes	Subthemes
1 Identity and stigmatised movement	
2 Ownership of demands	2.1 Structure and scheduling of movement
	2.2 Movement to increase focus
3 Body regulation	3.1 Movement to regulate sensory information
	3.2 Movement to release energy
	3.3 Movement to increase body awareness
4 Emotion regulation	4.1 Movement to express, evoke and intensify rewarding emotions
	4.2 Movement to express negative emotions

Data analysis

Reflexive thematic analysis aimed to make sense of themes that were present in the data, allowing for some subjective interpretation (Braun & Clarke, 2023). The data were read repeatedly for familiarisation, with reference back to the full blogs, with the researcher making notes of patterns and impressions. Codes were assigned to all concepts relating to movement of the body, and a codebook defined the codes. Codes were used as building blocks to develop themes, which provided a representation of the data as a whole.

Ethical approval was gained from York St John University Ethics Committee with close consideration of relevant ethical guidance (British Psychological Society, 2021a). Blog authors were not contacted. This followed careful reflection on the ethical considerations of conducting Internet-mediated research, and was not intended to de-contextualise or de-personalise the work of autistic authors. Only blogs that were written to inform and educate on a public platform were included in the data.

Community involvement statement

Community members were not involved in the study design.

Results

Four themes with accompanying subthemes are shown in Table 2.

Identity and stigmatised movement

Positive or negative judgements from others were experienced by the blog authors in response to their repetitive behaviours, which were determined by how 'tolerant' the environment is (blog-4). Stimming was defined as 'repetitive action that stimulates - provides sensory input' (blog-13), with there being a very wide range of movements that could be stimming behaviours (blog-28). When discussing dancing as a positive release of energy, one author anticipated negative reactions from others, and reviewed the environment before moving (blog-19). Movements were said to be deterred through 'teasing', which caused inhibition (blog-13). Some authors stated that repetitive movements were 'natural' (blog-13), and were not harmful, though aggression from others was an example of unintended harm (blog-28). Masking, mimicking and repressing self-stimulatory movements were said to be a lifelong effort for one author, which took constant focus (blog-7). However, repetitive movements were said to be a more positive use of energy than masking, and were 'freeing' (blog-7), and an 'integral' part of the authors being themselves (blog-28).

Negative perceptions of movements were also discussed in relation to differences in physical ability, such as being 'uncoordinated' (blogs-9, 18 and 28), which was described concurrently as being considered 'clumsy', 'uncooperative', or 'stubborn', such as in sports at school (blogs-9 and 18).

Ownership of demands

Structure and scheduling of movement. Physical activity was said to be something that provided 'routine and structure' (blog-8), and was one of few activities that the authors said they scheduled when life seemed uncontrollable (blogs-8 and 24). Physical activity was frequently reflected in accounts of daily scheduling (blogs-5, 8, 27, 28 and 32). Some physical activities provided opportunities for the authors to perform actions 'over and over', which they

valued (blogs-5 and 20). Scheduling physical activity was recommended by one author as a way to manage anxiety (blog-4). For one author, exercise was part of a grieving process, enabling the author to stay 'on track' while grieving: diet, exercise and sleep were part of them taking care of themselves (blog-14).

Movement to provide structure and scheduling was the most frequently discussed benefit of moving the body.

Movement to increase focus. Stimming was described by one author as a 'comfortable background signal' that helped the author to ignore distractions, such as when they were in an overwhelming or noisy environment (blog-13). Repetitive movements provided predictable sensations. Examples of repetitive movements included rocking, pacing, walking, waving their arms, stroking their body or jiggling (blogs-13, 18, 20 and 28). Movements enabled some authors to endure overloading settings for longer periods of time, to improve thinking abilities or focus, or to ignore distractions (blogs-13, 20 and 28). Physical movements were said to provide an 'easy' focus (blog-5).

Body regulation

Movement to regulate sensory information. Movement was widely reported to be a way in which the authors regulated sensory overload and confusion (blogs-13, 23, 27, 28). Movement could 'modulate' other sensory information, making it more manageable and able to be processed (blog-13). This meant that some authors could reduce the negative impacts of 'meltdown' or 'overwhelm' using movement as a coping strategy (blog-23). Movement took the form of stimming and physical activity. Examples of repetitive movements used to regulate sensory information included stroking parts of the body, squeezing their hands or holding a fidget toy (blogs-13 and 23). Examples of physical activities used for self-care and regulation included walking and other forms of exercise (blogs-26, 27 and 28).

Movement to release energy. Moving the body in a wide range of ways helped some authors to release energy, sometimes described as 'excess', 'excited', or 'anxious' energy (blogs-7 and 19). Stimming, such as hand flapping, pacing, or dancing could release an 'urge', be a 'pressure outlet', or an 'escape' (blogs-7, 19 and 20). Physical activity, such as running, could 'channel' energy in a useful way (blog-4). If not expressed through the body, energy felt to be repressed (blog-7). Repetitive movements could also be used as a way to increase energy, as a way to 'liven up' (blog-28).

Movement to increase body awareness. Some blog authors wrote about experiencing enhanced body awareness when their bodies were moving. One author said the 'need to walk' or engage in 'strong physical activities' helped them to know where their body 'is' and 'what it is doing' (blog-28). This author described this in the context of bumping into things and tripping over as part of poor interoceptive and proprioceptive abilities. Movement could provide predictability, and repetition of sensations. The increased body awareness helped some authors to 'fit' in the world or in environments that could otherwise feel frequently overwhelming or 'alienating' (blogs-23 and 32). One author said that moving their body made them feel like themselves again, 'so that I know it is me' (blog-32). For one author, movement of the body was part of trauma processing, where movement allowed 'release' and a return to feeling like themselves (blog-21). Movement helped some authors to feel 'in control' (blogs-28 and 32) or with 'agency' (blog-32).

Emotion regulation

Movement to express, evoke and intensify rewarding emotions. Some authors described movement as being a means to express positive emotions; hand flapping and dancing in particular were said to be expressions of joy (blogs-13 and 19), which 'intensify' pleasure or happiness (blog-13). Fitness and exercise, as well as rest and sleep, could be something to 'love', to 'obsess' over and to 'perfect' (blog-10). Running, cycling, dancing and stimming, could generate rewarding feelings, being 'amazing', 'destressing', 'exhilarating' and contributing to 'great mental health' (blogs-10, 15, 16, 19, 20 and 25). One author described how it felt 'right' to dance (blog-19). Movements could achieve relaxation, calm or comfort (blogs-13, 20 and 28).

Movement to express negative emotions. Running and physical activity were recommended as ways to manage worry and anxiety, where anxious energy could become useful and enjoyable (blog-4). Stimming was similarly said to be important for when feeling nervous (blogs-13 and 20), with one example being when somebody didn't know what to do or say (blog-20). Movement could modulate emotion – notably when emotion was felt strongly as a physical sensation (blog-13).

Movement for emotion regulation was the second most frequently discussed benefit of moving the body, second to structuring and scheduling.

Discussion

These findings normalise movements that are often stigmatised for autistic people (Jachyra et al., 2020; Kapp et al., 2019; Robledo et al., 2012). Autistic adults described a wide range of movements, including hand flapping and rocking, alongside non-stigmatised movements including dancing and physical exercise, as achieving the same benefits. Movement provided routine and interest, enhanced

focus, helped with sensory regulation, released energy, increased body connection, regulated emotion, provided time free from inhibition and strengthened self-identity. The findings provide more explicit rational from autistic authors of these functions, building on previous studies of stimming (Kapp et al., 2019) and exercise (Jachyra et al., 2020). Authorship of topics of lived experience by autistic people, including movement, and wider topics of gender identity (Adams & Liang, 2020) or social communication (Milton, 2014), should not be excluded from understandings.

Stigmatised and non-stigmatised movements were not distinguished by their function. In this study, all types of body movement had the potential to attract negative social judgement, for example, when autistic people showed differences with coordination, or when they moved in unexpected ways across contexts. The descriptions align with theoretical understanding that movements can differ in qualities such as rhythm and intensity for autistic people (Robledo et al., 2012). Some movements were avoided, as has been described before by autistic people (Jachyra et al., 2020; Kapp et al., 2019; Robledo et al., 2012). Suppression of movement can be associated with exhaustion, weakened self-identity and mental ill health (Bargiela et al., 2016).

Despite experiences of marginalisation, the authors in this study described a wealth of body movements that provided a natural and universal well-being resource. Akin to wearing ear plugs or sunglasses (Wada et al., 2023), chosen movements could increase resourcefulness to respond to stress. Movement also enhanced positive well-being, contributing to positive emotions and an authentic sense of self, which is a missing narrative from research literature (Petty et al., 2023). Often the well-being of autistic people is understood in terms of high rates of mental health cooccurrence and a limited evidence base for therapeutic interventions (Lever & Geurts, 2016; Spain et al., 2015), rather than personally-authored definitions of individual differences and strengths.

We offer a different framing of the body and its movement, from an emic perspective – not centring autistic experiences towards non-autistic standards, but recognising the different qualities of movement and the multi-fold benefits of moving freely and expressively.

Therapeutic interventions using the body need further development (DeJesus et al., 2020; Sorensen & Zarrett, 2014), informed by personal perspectives of autism. This study suggests the undervalued potential of movement to enhance well-being, though moving freely will occur as part of a process of disentangling autistic identity from disorders and negative judgements. Practitioners working with autistic people should explore the potential stigma experienced associated with their movements, including impacts of self-censorship. This would contribute to the required psychological formulation of mental ill health (British Psychological Society, 2021b). It may then be possible to explore the functions of movement described in this study, to develop a personalised well-being resource. Further applications of these findings include updates to trauma-informed working, exploring how body awareness can be used therapeutically in this context (Moran, 2010). Finally, the personal examples of movement and its meanings can inform supplementary guidance for the assessment and diagnosis of autism, moving beyond the limited labels currently available. Practitioners might consider the many appearances of movement, which enable autistic people to reduce distraction, sensory overwhelm, body confusion and emotional distress.

Limitations

This study hears the perspectives of a small number of autistic adults, who are likely privileged by their familiarity with technology and motivations to blog (Kim & Bottema-Beutel, 2019). The interpretation of the findings is also limited because the research was not co-produced (Pellicano & den Houting, 2022). We encourage readers to visit blogs, such as those hosted by Actually Autistic, and other sources of autistic authorship (Autscape, 2024), in order to engage with autistic writers directly. These views do not reflect the experiences of all autistic people.

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