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Expanded Descriptions of Autistic Repetitive Behaviours: a Constructivist Grounded Theory Review Exploring the Perspectives of Autistic Young People and Other Stakeholders

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Abstract

Restrictive and repetitive behaviours are part of autistic identity. However, in clinical decision making, there are too few representative examples, qualitative descriptors, and personal meanings of rituals and routines in particular. This systematic review sought descriptions of repetitive behaviours from autistic young people, their families, and professionals. Constructivist grounded theory analysis illustrated the unsuitability of diagnostic criteria alone in defining autistic behaviours. Repetitive behaviours were meaningful when described by autistic people. They provided coping strategies and a window of time when a person felt at ease in their world, with fewer cognitive, social, and sensory demands. The visibility, excess, and inflexibility of repetitive behaviours demonstrated an autistic person's responsiveness to demanding contexts. A definition of autistic repetitive behaviours is presented.

Keywords Autism · Rituals · Routines · Repetitive behaviours · Qualitative · Lived experience

Autistic identity is multifaceted and does not need clinical diagnosis to be legitimate (Cooper et al., 2023). However, descriptions of autism found within diagnostic manuals and clinical assessment tools influence who is and who is not recognised as being autistic. The main objective of this paper is to expand the available descriptions of autistic repetitive behaviours to include the differing perspectives of autistic young people, their families, and professionals.

“[T]he phenomenon of clinical diagnosis ensures that power over who is autistic, and how autism is defined, sits firmly in the hands of the medical establishment rather than the autistic community” (Fletcher-Watson, 2024, p. 258). Fletcher-Watson (2024) gives a comprehensive discussion of the tensions between neurodiversity and medical perspectives in the context of autism diagnosis. Descriptions of autism that align with neurodiversity affirming values validate difference, recognise strengths, and come from the advocacy of neurodivergent people (den Houting, 2019). And yet, there have been limited revisions to descriptions

of repetitive behaviours that are part of autism diagnosis (Bishop et al., 2013; Troyb et al., 2016; Uljarević et al., 2022), especially when compared with revisions that have been made to understanding differences in social communication for autistic people (Heasman & Gillespie, 2019; Milton, 2012). Repetitive behaviours have been re-conceptualised by autistic writers in ways that could inform research and expand diagnostic descriptions (Murray, 2018; McDonnell & Milton, 2014). However, currently, there is little supplementary guidance available to clinicians when they interpret assessment tools and diagnostic manuals with these advancements in mind. This prompts the need for a review of available evidence.

Clinical pathways for the assessment and diagnosis of autism throughout the world require healthcare professionals, autistic individuals, and their families to align with a conceptualisation of autism within the conventional medical paradigm, which assumes that autistic differences are problematic and are determined by an underlying pathology belonging to the individual (American Psychiatric Association, APA, 2022; Kapp et al., 2013; Pellicano & den Houting, 2022). Diagnostic tools do not benefit from theoretical updates or challenges to these medical assumptions (Vivanti & Messinger, 2021), meaning that “pre-existing assumptions” constrain diagnostic decision making. Vivanti and

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Messinger (2021) present a timeline of theoretical developments that underpin changes in how autism has been understood alongside updates to diagnostic manuals, which illustrates the lag between conceptual developments (including a neurodiversity affirming perspective) and their influence over clinical practice. This argument does not intend to polarise or criticise clinical practices. Much compassion is observed in clinical practice (Fletcher-Watson, 2024). Formal diagnosis of autism provides important understanding for many people and serves as a gateway to many essential supports (Crane et al., 2016; Equality and Human Rights Commission, 2010). A neurodiversity affirmative approach, which seeks to recognise autistic experiences without negative judgment (Chapman, 2020), can inform clinical practice (Sonuga-Barke, 2023). This study intends to contribute to neurodiversity affirming clinical practices.

Across the Diagnostic and Statistical Manual of Mental Disorders, DSM (APA, 2022), the International Classification of Diseases, ICD (WHO, 2022), and National Institute for Health and Care Excellence guidance (NICE, 2017), autistic repetitive behaviours are identified by some marker of intensity, insistence or inflexibility, or ritual that serves “no apparent external purpose,” such as lining up or sorting objects in a particular way. Behaviours can be thinking patterns, speech, body movements, or daily life activities, such as travelling the same routes or eating the same foods. By definition, repetitive behaviours that identify a person as autistic are “abnormal” or “unusual” and would not be carried out by non-autistic people in the same situations given their rigidity, excess, or persistence. An underpinning assumption is that repetitive behaviours demonstrate a deficit in adaptability to new experiences. The terms “rituals” and “routines” are unclearly defined and overlap in their descriptions. Importantly, these criteria make assumptions that would exclude many autistic people. Some people have been excluded from identifying as autistic, because of missed diagnosis or mis-diagnosis (Harmens et al., 2022; Hull et al., 2020; Lever & Geurts, 2016).

Research presenting the viewpoints of autistic people shows that it is not possible to describe all repetitive body movements as abnormal or unusual, because some movements, such as walking, dancing, or exercising, are not stigmatised, whereas others, such as “stimming,” can be (Joyce et al., 2017; Kapp et al., 2019; Petty & Ellis, 2024). Body movements are understood better than other repetitive behaviours (Bishop et al., 2013; Dunn et al., 2024). Whilst the underpinning functions of different repetitive behaviours might not be known to the observer, they are not without purpose when described by autistic people. Current descriptions of autistic repetitive behaviours also miss the social contexts and environmental factors that contribute to variability in how autistic people behave (Mesa & Hamilton, 2021), such as how autistic people might censor their ways

of behaving in order to camouflage with their neurotypical peers (Anderson et al., 2020; Pearson & Rose, 2021). This places a great deal of emphasis on non-standardised aspects of clinical assessment, variable clinical judgment, and psychological formulation, to infer beyond what is visible (British Psychological Society, 2021; Rutherford et al., 2016). Clinicians are unlikely to benefit from general definitions of rituals, which, for example, emphasise shared traditions within families (Turner et al., 2017). This definition is inconsistent with an assumption that autistic rituals are separated from those of others, which underpins clinical diagnosis. Likewise, autistic routines must be differentiated from general routines that contribute to the normalcy of everyday life (Fiese et al., 2002; Segal, 2004). What is missing is a conceptualisation of what characterises autistic repetitive behaviours specifically, with consideration of the underpinning functions shared by the widely variable expressions of autistic people (Dwyer, 2022).

This review sought an expanded definition of autistic repetitive behaviours, to include qualifying descriptions of what makes repetitive behaviours specifically autistic, examples of autistic rituals and routines, and a conceptualisation of the meanings of repetitive behaviours to autistic young people, their families, and professionals. This serves to better reflect both the stability of autistic characteristics and the varying degrees to which they are visible over time (Nelson, 2021; Shakespeare & Watson, 2001) by emphasising their function. The review seeks to understand the perspectives of autistic young people in particular, given the demands for improved understanding at this time of life, with the many transitions of contexts and services (McGovern & Sigman, 2005; Mesa & Hamilton, 2021). Diagnostic assessments for young people require reports from parents and carers, and assessment across contexts, where observable behaviours can vary (NICE, 2017). The perspectives of different stakeholders with insight into experiences that span childhood and early adulthood mean that the findings should support autistic people across the lifespan.

Methods

This constructivist grounded theory systematic review sought qualitative descriptions of the repetitive behaviours used by autistic young people as described by any stakeholder within published academic literature. This allowed commentary on differences between stakeholder perspectives and demonstrated the current state of the research literature. The authorship of the available descriptions is described in the findings to illustrate how autistic young people have been represented (Fletcher-Watson et al., 2019).

This study followed the method of using grounded theory to rigorously review literature proposed by Wolfswinkel

et al. (2013). The approach constructs new theory from qualitative data using systematic methods. We expand this method by applying constructivist grounded theory (Charmaz, 2014). A constructivist approach assumes a relativist epistemology, whereby the researcher assumes that there are multiple truths and realities within qualitative data, as opposed to there being an objective reality that can be accurately observed (Charmaz, 2014). The method places explicit value on the multiple and differing perspectives held by different authors. We believe this is a fitting way to approach a review of research conducted with and about autistic people (Pellicano & Stears, 2011). Grounded theory creates new understandings that are “derived from data, systematically gathered and analysed through the research process,” (Strauss & Corbin, 1990, p. 12); thus, theory is grounded in data (Glaser & Strauss, 1967; Punch, 2007). Constructivist grounded theory then allows the researcher to synthesise the findings from primary studies, making new links between understandings that are well-rooted, whilst being an active agent over the compilation of new theory (Mills et al., 2006; O’Connor et al., 2020; Wolfswinkel et al., 2013). This review sought a new conceptualisation of the repetitive behaviours of autistic young people. The review was conducted over five iterative tasks: define, search, select, analyse, and present (Wolfswinkel et al., 2013). The Results show the final task: Present.

Define

Included studies contained qualitative descriptions of the repetitive behaviours of autistic young people aged 10 to 19 years, who could be either formally diagnosed or self-identify as autistic. This reflects the systemic barriers to assessment that can exclude autistic people from receiving a diagnosis. Research designs that represent individuals who self-identify as autistic recognise complexities relating to access, and the meaning of clinical diagnosis to autistic people, and demonstrate trends in research towards these inclusive practices (Fletcher-Watson, 2024). Studies were included where the majority of the young people represented did not have co-occurring diagnoses of learning disability or ADHD. This is recognised as a study limitation; it intended to provide a niche of academic literature for initial theory development about autistic behaviours specifically (Wolfswinkel et al., 2013). However, the heterogeneity in samples

across the studies will be discussed. Variable study designs inevitably show different attempts to represent autistic people and real profiles of neurodevelopmental differences, which can include many cognitive, sensory, and movement characteristics, and co-occurring diagnoses (Hobson & Petty, 2021; Robledo et al., 2012; Vivanti & Messinger, 2021). Where possible, qualitative descriptions of the repetitive behaviours of autistic young people without learning disability or ADHD diagnoses were sought. Descriptions of repetitive behaviours could be written personally by autistic young people, family, clinicians, or academic professionals. The lead researcher kept a reflective diary of all decision processes (Charmaz, 2014). Only literature from 2013 was included to represent the latest assessment practices (APA, 2013). All studies were written in English and were available in full text.

Search

The authors conducted a search in APA PsycInfo, APA PsycArticles, Child Development and Adolescent Studies, CINAHL, ERIC, Ovid MEDLINE, and PubMed databases between August and December 2022. The authors carried out forward and reverse citation searching. Additional sources informed the search strategy but were not retrieved as study data. A search of autism data, EThOS, The British Library, and PubMed grey literature databases located relevant conference proceedings, reports, and governmental papers. Support groups and charities for autistic people affiliated with the National Autistic Society, The Autism Network, and The Autism Page were contacted to request additional literature and the author read literature published prior to 2013. Search terms were developed from the research question and were expanded to maximise the number of returns (Petticrew & Roberts, 2005). The search string is shown in Table 1. The four components targeted by the search terms were young people, autistic, repetitive behaviours, and qualitative studies. The search strategy sought descriptions of any behaviours that involved repetition to allow the inclusion of personally meaningful descriptions and examples.

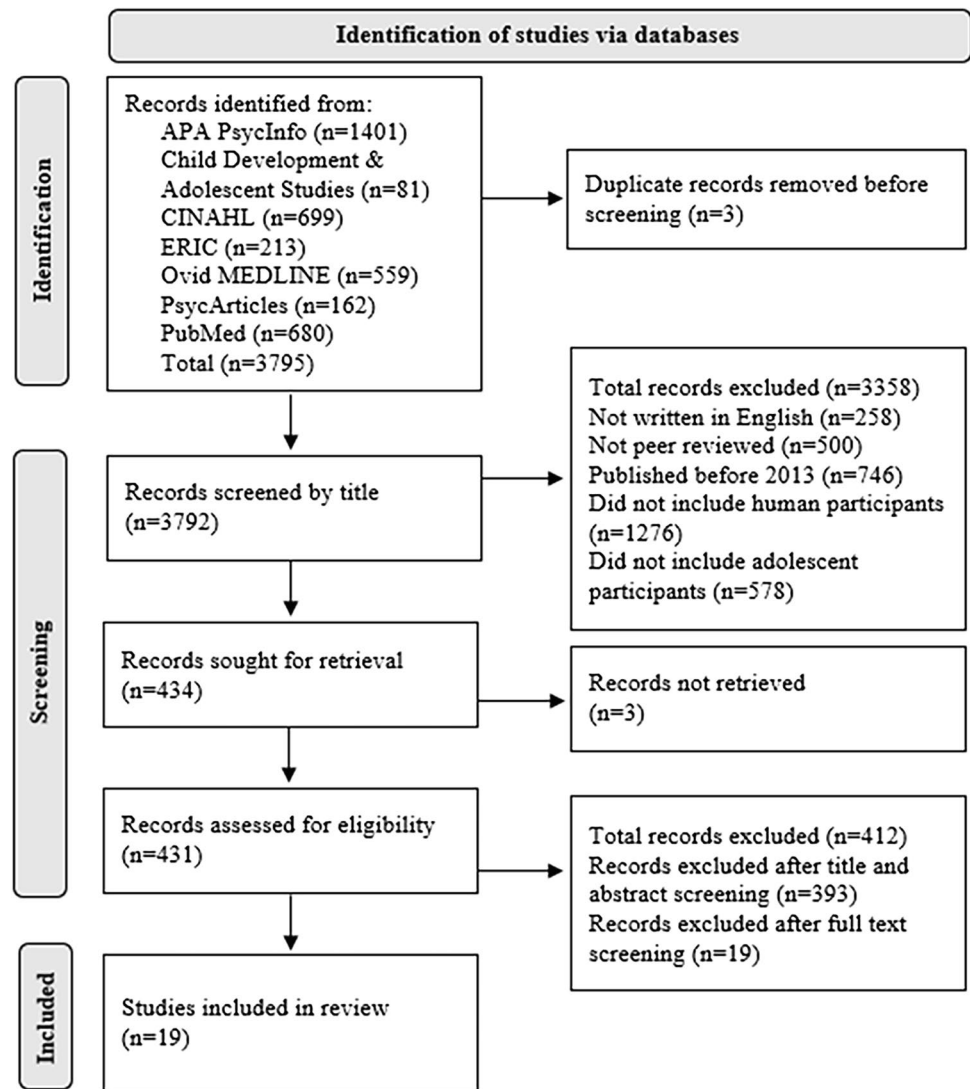
Select

The search returned 3795 studies (see Fig. 1). Duplicate texts were removed. Studies were screened by title and

Table 1 Systematic review search string

| |
|--|
| Search string |
| (adolescent OR child OR teen OR young person OR young people OR youth) AND (ASD OR asperger’s OR aspie OR aspy OR autism) AND (behaviour OR focused OR obsessive OR repetitive OR restrictive OR ritual OR routine OR RRB OR stereotyped) AND (constant comparative method OR content analysis OR discourse analysis OR ethnographic OR field study OR focus group OR grounded theory OR hermeneutic OR lived experience OR narrative analysis OR observation OR phenomenological OR qualitative OR thematic analysis) |

Fig. 1 PRISMA flowchart showing study screening and inclusion



Adapted from Page et al. (2021).

abstract. Thirty-eight remaining full texts were screened independently by the first author and a second researcher who was external to the research team. The main reasons for exclusion after full text screening were an absence of qualitative descriptions and young people having a co-occurring diagnosis of ADHD. Disagreements were resolved through discussion. Nineteen studies were included.

Included studies were appraised for methodological rigour and possible biases using the Critical Appraisal Skills Programme, CASP, Qualitative Studies Checklist (Long et al., 2020). These considerations were particularly important for the review conclusions given the importance of autistic people being fairly represented and understood within research conducted about them (Fletcher-Watson et al., 2019). Each study was appraised against ten criteria,

such as “Has the relationship between researcher and participants been adequately considered?,” which were rated as either “yes,” “can’t tell,” or “no.”

Analyse

All studies were read in full in random order (Wolfswinkel et al., 2013). All descriptions of repetitive behaviours and their surrounding contexts, also called insights, were highlighted. To ensure that relevant descriptions were retained, a second researcher independently highlighted insights from 20% of texts. A third researcher independently highlighted insights from a further 10% random sample of texts. Descriptions of repetitive behaviours were highlighted in all 19 studies. Highlighted text formed a qualitative dataset for

coding. Data underwent initial, focused, and theoretical coding (Birks & Mills, 2005; Wolfswinkel et al., 2013). These coding processes collected qualitative data whilst simultaneously analysing them to construct and refine new conceptual understandings (Charmaz, 2014; Glaser & Strauss, 1967).

During initial coding, the researcher was open to exploring conceptual possibilities, rather than trying to fit descriptions of repetitive behaviours to pre-existing understandings. Codes can be thought of as “sensitising concepts,” which keep close to the participants’ own language and draw the researcher’s attention to participants’ experiences and social contexts (Charmaz, 2014). Insights were read and re-read to represent descriptions from a bird’s eye view. Through focused coding, the researcher noticed the relationships between initial codes, and grouped them into categories that connected them conceptually (Carmichael & Cunningham, 2017). A category is a higher-order interpretation of individual descriptions found across studies. For example, avoiding a play area or instructing a child to eat a particular food became examples of family members controlling or modifying repetitive behaviours. Memo writing was used to support this process, whereby the researcher noted the possible relationships between appearing categories (Charmaz, 2014; Strauss & Corbin, 1998; Wolfswinkel et al., 2013). Finally, main categories were created through theoretical coding to represent all conceptual categories and the relationships between them. Main categories represent how well the available literature answers the research question (Birks & Mills, 2005). The research question was: how are autistic repetitive behaviours defined when described personally by autistic young people, their families, and clinician or academic professionals? Essentially, theoretical coding allows the construction of new theory that represents as much knowledge as is available on a selected topic. A codebook was used to map where each study contributed to each category, allowing for commentary on the authorship of differing descriptions. An explicit goal of the analysis was to answer “why” questions (Charmaz, 2014), such as why repetitive behaviours are used, why they differ between individuals or places, or why there are differing assumptions of their value. The constructivist grounded theory method guides the researcher to “tolerate ambiguity” (Charmaz, 2014, p. 290), to represent co-constructed realities of repetitive behaviours used by autistic young people.

Results

Characteristics of the 19 included studies can be found in Table 2, along with the CASP score given to each study. A conceptualisation of autistic repetitive behaviours is then presented. Three categories emerged from the analysis: (i) influencing contexts and value judgments, (ii) meanings of

repetitive behaviours, and (iii) responses to repetitive behaviours, shown in Table 3 with underlying subcategories and codes.

Quality Appraisal

Eighteen of the 19 studies were identified as being high quality, with ratings of “yes” for a minimum of seven out of 10 items. The exception was Obst et al. (2022), which was a report written by clinical practitioners and was poorly summarised by the CASP assessment. The item that received the most “no” ratings was consideration of the relationship between the researcher and participants. Items receiving the most “can’t tell” ratings were considerations of ethical issues such as informed consent and the amount of detail provided in data analysis (such as how much original data was presented, consideration of contradictory data and potential bias or influence of the researcher). Quality appraisal therefore suggested that reflexivity, consideration of participatory frameworks, and more detailed reporting of ethical standards of researching with autistic people are priority areas for improved design.

Study Characteristics

Six studies were conducted in the USA, four in the UK, three in Australia, three in Ireland, and one study each in Hong Kong, Japan, and Spain (see Table 2). This review summarises global understandings of repetitive behaviours for autistic people, which is both a strength and a limitation. Whilst autism is defined by international diagnostic manuals, there is variability in how autism is understood across cultures (de Leeuw et al., 2020). This limits the reach of any one conceptualisation for understanding the experiences of autistic people.

As shown in Table 2, studies presenting qualitative descriptions of autistic experiences from young people themselves originated primarily from the UK, with four of the eight studies representing autistic perspectives originating from the UK, and then America, Australia, and Japan to a lesser extent. Young people’s perspectives were presented in all studies from the UK. Conceptualisations of repetitive behaviours that attributed personal meaning to repetitive behaviours, and recognised their value in providing reassurance or comfort in response to demands and environments experienced by the young person, were most fully described by studies from the UK and Ireland (S4 and S16). This likely reflects the advancements in inclusive and participatory research practices and the conceptualisation of neurodiversity affirming practices developing in the UK (Fletcher-Watson, 2024; Pellicano & den Houting, 2022; Sonuga-Barke, 2023). The influence of diverse cultural contexts on repetitive behaviours needs further exploration.

Table 2 Characteristics of the included studies

| Study author, year and title | Study location | Authors of the description of repetitive behaviours | | | Number of CASP 'yes' ratings out of 10 | Study design |
|--|----------------|---|--------|-------------------|--|--|
| | | Autistic young person | Family | Professional only | | |
| S1 Bagatell et al. 2014. Routines of families with adolescents with autistic disorders: A comparison study. | USA | | yes | | 8 | Quantitative and qualitative survey. Cross-sectional design. |
| S2 Boyd et al. 2014. Families of children with autism: A synthesis of family routines literature. | USA | yes | yes | yes | 7 | Literature review. |
| S3 Curtiss et al. 2021. A dialectic of control and acceptance: Mealtimes with children on the autism spectrum. | USA | yes | yes | | 9 | Qualitative observation and interview. |
| S4 Daly et al. 2022. Family life and autistic children with sensory processing differences: A qualitative evidence synthesis of occupational participation. | Ireland | | yes | | 10 | Literature review. |
| S5 Hellings et al. 2022. Benefits and challenges of assistance dogs for families of children on the autism spectrum: mothers' perspectives. | Australia | | yes | | 9 | Qualitative interviews and photovoice. |
| S6 Jones et al. 2021. Identifying the essential components of strength-based technology clubs for adolescents with autism spectrum disorder. | Australia | yes | yes | | 10 | Qualitative observation, focus groups and interviews. |
| S7 Kirkpatrick et al. 2019. Qualitative study on parents' perspectives of the familial impact of living with a child with autism spectrum disorder who experiences insomnia. | Ireland | | yes | | 8 | Qualitative focus groups. |
| S8 Lei et al. 2020. Evaluation of a transition to university programme for students with autism spectrum disorder. | UK | yes | | | 9 | Intervention evaluation. Quantitative and qualitative questionnaire. |
| S9 London et al. 2020. Animal assisted therapy for children and adolescents with autism spectrum disorder: Parent perspectives. | Australia | | yes | | 9 | Qualitative interviews. |
| S10 Mackay & Parry. 2015. Two world views: Perspectives on autistic behaviours. | UK | yes | yes | | 8 | Qualitative interviews and video diaries. |
| S11 McLaughlin & Rafferty. 2014. Me and 'it': Seven young people given a diagnosis of Asperger's syndrome. | UK | yes | | | 7 | Qualitative interviews. |
| S12 Mumbardo-Adam et al. 2021. How have youth with autism spectrum disorder manage quarantine derived from Covid-19 pandemic? An approach to families perspective. | Spain | | yes | | 9 | Quantitative and qualitative questionnaire. |
| S13 Ng & Ng. 2022. A qualitative study on the experience of stigma for Chinese parents of children with autism spectrum disorder. | Hong Kong | | yes | | 9 | Qualitative interviews. |

Table 2 (continued)

| Study author, year and title | Study location | Authors of the description of repetitive behaviours | | | Number of CASP 'yes' ratings out of 10 | Study design |
|--|----------------|---|--------|-------------------|--|--------------------------------|
| | | Autistic young person | Family | Professional only | | |
| S14 Obst et al. 2022. Supporting children on the autism spectrum as they experience the challenges of COVID-19. | USA | | | yes | - | Practitioner report. |
| S15 Parry et al. 2021. Dental visits for autistic children: A qualitative focus group study of parental perceptions. | Ireland | | yes | yes | 8 | Qualitative focus groups. |
| S16 Pavlopoulou. 2020. A good night's sleep: Learning about sleep from autistic adolescents' personal accounts. | UK | yes | | | 8 | Qualitative photo elicitation. |
| S17 Sethi et al. 2019. Parent and professional perspectives on behavioral inflexibility in autism spectrum disorders: A qualitative study. | USA | | yes | | 9 | Qualitative focus groups. |
| S18 Warren et al. 2021. Parent-identified strengths of autistic youth. | USA | | yes | | 8 | Qualitative interviews. |
| S19 Yamamoto. 2021. How children with autism spectrum disorder perceive themselves: A narrative research. | Japan | yes | | | 10 | Qualitative interviews. |

Table 3 Main categories, subcategories, and codes within a constructivist grounded theory of autistic repetitive behaviours

| Category | Influencing contexts and value judgments (S1, S2, S3, S4, S6, S8, S9, S10, S13, S15, S16, S17, S18) | Meanings of repetitive behaviours (S4, S6, S10, S15, S16, S17) | Responses to repetitive behaviours (S1, S4, S6, S7, S10, S17) |
|---------------|--|---|--|
| Subcategories | Places and the visibility of repetitive behaviours Expectations of repetitive behaviours Deviations from the routines of other people Perceived missed opportunities and disadvantages of repetitive behaviours | Reducing cognitive demands Reducing unpleasant experiences Strengthening agency and identity Connecting with other people Contentment from the world making sense | Co-ownership of overwhelm Reciprocal benefits of repetitive behaviours Encouragement and celebration of difference Problematising of repetitive behaviours Control and modification of repetitive behaviours |
| Code examples | Impact of the young person's repetitive behaviour on the family | Seeking absolute certainties | Avoidance of certain places where repetitive behaviours are seen by other people |

It was beyond the scope of the current study to explore this adequately.

Autistic young people's characteristics were inconsistently reported. When characteristics were reported, rationale for the inclusion or exclusion of autistic individuals as study participants based on co-occurring characteristics was rarely given. One study included young people with co-occurring mental health conditions and intellectual disability; one study included young people with developmental delay; one study included young people with ADHD, intellectual disability, or language impairment—in these three studies, the majority of the young people disclosed no co-occurring conditions. In one study, the young people had co-occurring anxiety and/or ADHD, and/or dyspraxia, and a smaller number were reported to have a learning disability. One study included some young people with co-occurring ADHD diagnosis. One study had variable inclusion criteria across different conditions, with some young people reported to have an intellectual disability. In other studies, one study excluded young people with visual or hearing impairment; one study excluded young people with physical disability. No other cognitive, sensory, or movement characteristics were described in any study. The majority of the young people represented in this review were reported to be autistic without co-occurring neurodevelopmental or mental health diagnoses. Whilst these study designs vary in their representation of the real profiles of neurodevelopmental differences and co-occurring diagnoses (Hobson & Petty, 2021; Robledo et al., 2012), inconsistent descriptions of autistic participants in research and the underreporting of inclusion decisions with rationale in particular demonstrate where improvements can be made in future research.

Authorship of Descriptions of Autistic Repetitive Behaviours

Autistic young people were the least represented group of authors, as shown in Table 2. This is also reflected in the

presentation of results to follow. The majority of studies represented family members and professionals. Importantly, different author groups demonstrated different assumptions of repetitive behaviours, including differing perceived functions and impacts on self and others. A hierarchy of voice emerged, whereby some authors were assumed to have more authority when defining repetitive behaviours, to be discussed.

Descriptions of repetitive behaviours were given by autistic young people in eight of the 19 studies. However, young people were explicitly asked about their repetitive behaviours in only one study (S16). In other studies, experiences of repetitive behaviours were part of broader narratives about being autistic, such as experiences of receiving a diagnosis (S11), or attending a programme supporting transition to university (S8). These studies responded to problem areas that had been identified for intervention.

When autistic young people described their repetitive behaviours, they referred to likes, dislikes, favourites, games, or hobbies. For example, "I just absolutely adore Lego" (S6), "...there are many things I don't like. I also don't like certain foods mixed together, like chips and gravy" (S10), and "I read my favorite book" (S16). First, this demonstrates personal choice over repetitive behaviours. Second, it begins to illustrate the personal meanings of different behaviours, as presented in the conceptual summary. The same personal motivations of autistic young people were presented in descriptions given by some family members, who also noted the likes and needs of a young person. For example, "He does not like tight fitting clothes and clothes with tags," and "he needs like a minute or two [of chewing]" (S4). However, people other than the young person most often assumed that these behaviours were meaningless, and were carried out without personal choice. For example, "[Harry's] obsessions are, can become, not tiresome... but it so preoccupies him, and it so directs, so controls his life, that it can be really difficult sometimes... it's controlled huge amounts, chunks

of our lives” (S10). The authors of this study summarised examples of mealtime preferences as “chores, requiring control and management” by the family (S10). A challenging mealtime behaviour described in another study was a young person “complaining about what is served” or “refusing to eat what is served” (S3). The simultaneous experiences of autistic young people included feeling nervous or anxious at these times (S3). In other studies, parents said that repetitive behaviours showed “what’s wrong with him” when a young person stopped frequently when walking and hit the fence or floor (S9). This was described by the study authors as being an example of “maladaptive behaviours” and “symptoms” (S9). Not playing with other children and “just walking around” were “socially unacceptable behaviors” in another study, meaning that parents felt socially isolated and could not live “a normal life” (S13). Whilst these examples share an important perspective of some family members, this review illustrates more prevalent contributions of othering and problematising perspectives compared with the inclusion of neurodiversity affirming perspectives in academic literature.

More frequent authorship of repetitive behaviours was by parents of autistic young people, represented in 14 of the 19 studies. Parents were asked for their insights into the repetitive behaviours of autistic young people as part of study designs. However, the most dominant voice was that of professionals, in part due to study authors offering summaries. Professional authorship denotes a researcher, academic, or clinician offering an interpretation of the behaviours of an autistic young person. Individual behaviours were commonly obscured by summarising labels, which were shown to carry authority: “Ten-year-old Jonathan, for example, told me, ‘My games are definitely an obsession, as mummy keeps reminding me’” (S10); “The most commonly reported symptoms included maladaptive behaviours... routine dependency” (S9). Mackay and Parry described how dominating discourses can change the interpretation of repetitive behaviours: “Parents in the study interpreted obsessive behaviour through the lens of medical and psychiatric discourses. Through this lens, obsessive behaviours indicated something wrong with their children. Within a medical discourse, obsessive and ritualistic behaviours are subject to control, management and modification” (S10). This disability perspective was also discussed by Boyd et al. (S2).

Conceptual Summary

This conceptual overview attempts to summarise all perspectives whilst appreciating differences and ambiguities in understanding. Rather than static understandings being owned by different stakeholders, the summary illustrates how defining characteristics of autistic repetitive behaviours change over contexts. The summary values the multiple

truths and realities that exist within qualitative data, aligned with constructivist grounded theory (Charmaz, 2014).

Influencing Contexts and Value Judgments

Places and the Visibility of Repetitive Behaviours

The places where repetitive behaviours were seen influenced how they were defined. When a ritual or routine was observed in a public place, most commonly behaviours were said to cause difficulty for people other than the young person. Repetitive behaviours were described without discussion of the personal meanings of them. For example, “Noel felt that the dog helped to reduce maladaptive behaviors in his child,” (S9) and “when we go to the park, she often displays some odd behaviors that make people stare at us” (S13). Parents described wanting to avoid places where repetitive behaviours seemed unwelcome: “I need to feel that I can control the situation before we go out... I don’t want to take him out” (S13). In another study, families avoided going shopping or going on holiday, “Even vacation... the whole time you’re more stressed out than if you were at home... it just became not worth it so much to do things like that” (S17). Public places seemed to force a negative value judgement. There were no accounts from young people to offer an alternative understanding on these occasions.

Intricately linked with places that problematised repetitive behaviours was a response to change the young person’s behaviour or control the situation where it was seen: “Therefore, when there are many people, we don’t dare or don’t want to play there” (S13). Repetitive behaviours that were seen at school, such as rocking a chair or not sitting still, were examples of behaviours in places where parents felt stigmatised (S13). This literature collectively presented an assumption that repetitive behaviours shown by autistic young people caused difficulties for them in education settings (S6, S8, S13 and S18). “A preference for routine, certainty, and other facets of the repetitive behaviours domain in autism may also mean that students are ill-equipped to adjust to the changes in everyday routines and living required” (S8). Contrasting perspectives, such that repetitive behaviours were a response to academic environments, were not foregrounded in this literature. Available accounts from autistic young people described the importance of members of staff (S6) and peers (S8) in education settings understanding and accepting autistic differences so that they felt included. Dental appointments were another place where strategies were sought for behaviour change (S15): examples of repetitive behaviours that caused difficulty for health professionals and families included a young person repeatedly replaying new scenarios ahead of time, asking repeated questions, or keeping a limited diet (S15). Based on

this literature, autistic repetitive behaviours would be defined by their negative impacts on tasks of daily life.

Expectations of Repetitive Behaviours

Repetitive behaviours were defined differently by parents when they were observed in places that welcomed expressiveness and saw repetitive behaviours as reflecting positive characteristics. For example, within a club supporting computer-based activities (S6), repetitive behaviours were understood as being valuable for new skill development. “Ritualistic behaviour patterns, which involved competencies that might be considered useful, such as maths, were described by parents in terms of gifts and skills... Parents described these ‘valued’ behaviours as ‘extraordinary’ and ‘amazing’... sometimes making reference to Einstein and other famously gifted individuals” (S10). Value was placed on the application of skills to a future career. “Another parent described the importance of their son discovering robotics... his whole path already mapped out” (S6). Repetitive behaviours could indicate an autistic young person thriving or flourishing: “many expressed that their youth flourished with clear expectations, guidelines, and consistency... when given a predictable and consistent routine... just fascinated by technology and mechanics... I mean they just could be fantastic mechanical engineers. They got great ideas” (S18). An unstable definition of repetitive behaviours would come from looking only to temporary contexts, where examples of moving, thinking, or talking repetitively could be either problematised or celebrated, rather than being accepted as a consistent personal resource. Meanings attached to repetitive behaviours are context dependent.

Deviations from the Routines of Other People

Repetitive behaviours were most problematised in the available literature when they interrupted or deviated from expected daily life activities, when they “complicated everyday life” (S10). These descriptions came mostly from families and professionals. Repetitive behaviours deviated from and required extra planning by families for “even the simplest of tasks” and prevented engagement in “meaningful family activities” (S17). Mealtimes were a particular context where families changed their anticipated routines. “For many families, mealtimes were rarely a time for togetherness emotionally or physically” (S4). Study authors noted that “dinnertime was characterized by chaos and lack of meaningful interaction,” (S1) or mealtimes were “often characterized by stress and problematic behavior” (S3). Families might prepare a number of different meals, avoid eating in new places, use the same utensils, or keep to limited, familiar foods (S1 and S17). Bedtimes were another priority context for intervention (S1, S4, S7, S16 and S17). Difficulties

falling asleep and examples of repetitive behaviours related to young people choosing familiar foods before bed, preferring certain clothing or objects, or engaging in a particular game or hobby before going to sleep (S7 and S16). “Many of the children described as being inflexible shared a need for consistency. This manifested in their interactions with toys, such as having the same toy accompany them during bedtime” (S17). In this study, repetitive behaviours were consistently described as belonging to the autistic young person and were used without personal choice. For example, “their children’s inability to adjust in these situations often led to such behaviors as agitation, repetitive questioning, increased anxiety, or in some cases tantrums, violence, or self-injurious behaviors” (S17). Repetitive behaviours could be “accepted” or “tolerated” or “flexed” around by families (S17). Alternatively, at bedtime, autistic young people said that repetitive behaviours such as playing a game to keep to a familiar sequence leading up to bed, rehearsing the day, or talking through the plan for the next day, helped with feeling calmer, safer, and having fewer worries before sleeping (S16). This was discussed by Boyd et al.: “For families of children with ASD, there is a dual nature to routines. On one hand, routines help because they provide predictability, which often allows the child to participate in family occupations. On the other hand, the child’s strict adherence to routines does not allow for ‘improvisation’ and can lead families to feel that they are ‘trapped in routines’ partly due to the child’s rigidity and behavior” (S2). These times of day will provide particularly beneficial talking points for clinicians within assessments of autism. They also provide opportunities to better understand the young person’s perspective at these times, which was not explored in much of this literature.

Perceived Missed Opportunities and Disadvantages of Repetitive Behaviours

One assumption presented in this review was of a dichotomy of “either functional or non-functional” behaviours (S10). A synonymous term to non-functional behaviours was challenging behaviours. There were examples of parents perceiving repetitive behaviours as causing missed opportunities for positive experiences where in the same situations a young person described a positive experience of sameness—a preferred experience. This illustrates the importance of appreciating the differing perspectives that underpin descriptions of behaviours. As discussed by Boyd et al. (S2), there can be a “paradox” between the needs of an autistic young person, “predictability, which often allows the child to participate in family occupations,” and the change from the preferred patterns for the wider family. There were examples of missed opportunities to eat in different places (S4 and S17) or spend time together as a family enjoying meals (S1). This

is particularly important when defining repetitive behaviours for young people given their interconnections with family and support systems. Repetitive behaviours received negative judgment when they were perceived as hindering friendships, education, or career progression. Study authors summarised that repetitive behaviours contribute to segregation or isolation and bullying. “Even for autistic young people who report having friends, friendships are often not truly reciprocal as socialisation rarely takes place outside of pre-defined structured settings” (S8), and “restricted or limited interests leading to poor social relationships for the child,” (S17) with one parent saying, “[inflexibility] opens them up to bullying” (S17).

Whilst there was evidence of parents describing autistic sensory processing differences and their interaction with some repetitive behaviours, a response to some repetitive behaviours was to overcome them: “Huge sensory issues... you just keep going with it, he did get used to it, there is still a fight in the morning but it’s a lot better. Before he used to lock his jaw so you couldn’t even get the toothbrush in” (S15). “During the observation there was a conflict regarding which order her son should eat his applesauce and yogurt (he was willing to eat both). Lindsay described what she was thinking during the conflict. Just sit down and eat it because those are two things that you like. Just sit down and eat it” (S3). Autistic repetitive behaviours might then be defined by the ways in which they disrupt necessary tasks of daily life for young people. These were conditions under which repetitive behaviours were responded to with control or modification. An understanding of why repetitive behaviours are seen in these contexts is illustrated by the personal perspectives of autistic young people who narrated their personal choices and the benefits of repetitive behaviours, presented next.

Meanings of Repetitive Behaviours

Autistic young people consistently described their repetitive behaviours as having valued functions. These were to reduce cognitive demands, to reduce unpleasant experiences including sensory demands, to strengthen agency and identity, to connect with other people, and to feel contentment from the world making sense.

Reducing Cognitive Demands

Cognitive demands included having to shift focus when there were interruptions to an activity, which young people wanted to reduce. For example, “I prefer my CDs ‘cause they don’t have adverts to interrupt” (S16). “No other book, no because then I might need to put too much effort reading new words or thinking about the meaning of the words... This would actually make me worry” (S16). Another demand was responding flexibly to new expectations such as within

healthcare appointments: “She will ask a hundred questions every day about the thing that’s happening in 2 weeks’ time, and then it plays on them and then they will lack sleep... Repeat the same thing do not change it because then it just confuses them all again” (S15). Repetitive behaviours could help young people to focus their minds as a reprieve from worrying. “I have all these little items that I like to collect too, which in many ways attract my interest. I find it very relaxing to explore their symmetry and patterns... their beauty stays with me and makes me feel good... it is a way to keep all worries away as your mind focuses on the beauty of these items” (S16). Asking questions was a way to prepare ahead of new situations or replay and make sense of what had happened before (S17). Writing lists similarly supported wellbeing by reducing demands to problem solve and think flexibly in the future: “Writing a list about what’s going to happen the day after or plan A and plan B so that I feel prepared, I feel I have some sense of a plan” (S16). Time with parents before bed could provide reassuring conversations, to “review the day,” or “plan for the day ahead,” “to wind down” and “feel safe,” including counting down to upcoming events (S16). Replaying scenarios from the day or planning for the demands of the day ahead were discussed alongside using guided meditation phone apps, breathing deeply, or mental rituals of “memoriz[ing] different details about the clothing, the faces and other stuff about the characters” (S16).

Reducing Unpleasant Experiences

The following example illustrates how repetitive behaviours reduced unpleasant experiences for an autistic young person: “I also don’t like certain foods mixed together, like chips and gravy. That may seem weird, but just imagine chocolate sauce on your sausages and you’re halfway to understanding” (S10). Repetitive behaviours could also provide stability, clarity, and reassurance for a young person (S4). “Self-directed activities which involved high levels of repetition” could be “calming” (S16). Examples included “drawing, watching favorite animated characters cartoons, fantasy-themed objects such as role-playing cards, exercising favorite hobbies (gymnastics and playing music), playing video games and interacting online with others who share similarly focused interests” (S16). Choosing a familiar scene in a film “excites me and calms me at the same time” (S16). Young people said that benefits might include “stay[ing] calm” or “sleep[ing] faster” (S16). Family members and clinicians described aggression or harm to self when a young person was not able to use repetitive behaviours (S17).

Accounts from autistic young people showed repetitive behaviours to be a meaningful strategy for regulating negative experiences including sensory experiences. “Autistic adolescents explained that they had personalized these

general sleep rules to fit their need to achieve the right level of sensory stimulation... I am sensitive during sleep time. Having a specific set of clothes helps me focus less on my skin sensations... blocking unwanted environmental noise” (S16). Repetitive movements could regulate bodily experiences, such as drumming to help “release all energy” or “fidget toys to keep my hands busy” (S16).

Strengthening Agency and Identity

In one study, repeatedly interacting with a character in a game helped autistic young people to “develop their interpretations of self and other” and explore “the abilities, commitments, intentions and desires they associated with the objects (fictional characters),” according to the authors’ summary (S10).

Connecting with Other People

Autistic adolescents described contexts within which they enjoyed friendships, which were places where they felt welcomed and where repetitive behaviours were expected, where there was encouragement and celebration of difference: “I like meeting with other people, getting to know them, and, if they’re pretty nice and if they like the same things I like, we actually start becoming good friends” (S6). Repetitive behaviours could help connections with other people: “I sometimes go online to chat a little bit as I play... It is about feeling less lonely, feeling confident to chat online about things I am really good at” (S16).

Contentment from the World Making Sense

Finally, repetitive behaviours supported a sense of contentment, or being ok in the world. A young person said: “I go to bed tired from things that I have enjoyed doing... feeling good at bedtime ‘This evening was not wasted, I did things I liked’ helps as I close my eyes” (S16). In another study, this perspective was provided by family members: “Indeed, the purpose of routines went beyond this and served to provide reassurance to the autistic child, that once a routine was in place the child ‘knows that all is well with the world...’” (S4).

Where repetitive behaviours could be perceived by people as being too strict, routinised, rigid, or trapping (S2), the same predictability was what autistic young people described as easing and helping to allay worries, promoting comfort, relaxation and calm, reducing sensory demands, and aiding sleep (S16). Repetitive behaviours were described by people other than young people with absolute qualifiers, such as, “everything had to be...” (S10), “always...” (S7), “all of the time... in every way” (S17). For example, an “insistence on” colours, presentation of food, or order of eating (S10).

Repetitive behaviours could seem to take too much time or non-priority focus. However, absolutes could represent a goal for autistic young people who sought predictability in close reciprocation with how demanding an environment was. The fixed or reliable benefits of repetitive behaviours were part of their valued functions. The behaviours took the amount of focus and time that was needed.

When described by autistic young people, repetitive behaviours would be defined by an underpinning desire to lessen overly demanding cognitive and unpleasant sensory experiences, to facilitate connection with other people, and strengthen sense of self. A definition of autistic repetitive behaviours that expects deviation from routines of daily life might erroneously suggest that autistic young people lack responsiveness to their surroundings. A more accurate interpretation would be to characterise repetitive behaviours as being a demonstration of responsiveness to certain, more demanding contexts for autistic young people. Supportive actions would facilitate fewer demands in the environment, or promote repetitive behaviours that achieve contentment.

Responses to Repetitive Behaviours

In addition to responses to repetitive behaviours discussed (including controlling, modifying, and sometimes celebrating difference), a different response was described when demands or overwhelm were co-owned by autistic young people and their families—when there were reciprocal benefits of repetitive behaviours.

Co-ownership of Overwhelm

Repetitive behaviours were accepted when families shared anxiety about anticipated overwhelm. Demands such as competing timelines in mornings were normalised (S1). There were shared concerns that sleep could be disrupted for everybody (S4 and S7), and that unpredictable demands could be anxiety-provoking (S4). One study reported that all families have difficult times in the day, such as managing busy periods, different schedules, and transport needs (S1). Repetitive behaviours were then co-owned by autistic young people and their families, which allowed mutual benefits. Routines provided an opportunity for whole families to feel reassured, comforted, and confident in “what can be a frightening world” (S4). Repetitive behaviours were valued when there was a shared reality of being “on the same page” (S17). Co-ownership of possible overwhelm provided an opportunity to focus on individual strengths and share outcomes such as togetherness (S4). Repetitive behaviours had reciprocal benefits of enjoyment and belonging when people shared interests (S6 and S10), or when interests leveraged skill development (S6). There were examples of interventions that supported whole family participation (S1 and

S2). Examples of repetitive behaviours that were accepted, such as undressing in a set sequence (S4), or being immersed in an interest for long periods of time (S6), aligned with the same behaviours described as problems or symptoms of autism at other times. Therefore, there was inherent meaning attributed to repetitive behaviours when their function was appreciated.

Revised Descriptions of Autistic Rituals and Routines

A definition of autistic rituals constructed from the personal perspectives of autistic young people states that rituals belong to the individual rather than the family. They have understandable functions and personal meanings beyond the observable actions, which include focusing worries or busy thoughts, providing a story of the experiences of the day, promoting agency and ownership of identity, or achieving contentment that things are completed or well prepared. Specific examples of autistic rituals included enacting or replaying aspects of fictional characters or moving the body in a familiar way. The essential characteristics of these examples were that they were pleasurable, beneficial to the young person, and motivated by personal choice. When described by people around the autistic young person, autistic rituals often disrupted family life.

Routines linked together several sequential steps or rituals. They occurred around the same time each day, often when getting ready in the morning, managing mealtimes, or preparing for bed. Routines discussed in this review were often co-owned by young people and their families and provided a familiar structure in preparation for anticipated demands.

Rituals and routines were not consistently distinguishable from each other.

Result Summary

The different perspectives illustrated by this review show an unstable characterisation of autistic repetitive behaviours, which often omits the personal meaning of these behaviours to autistic young people. The importance of the contexts within which repetitive behaviours are viewed is rarely acknowledged. Autistic repetitive behaviours could not be identified by their appearance, but by what was valued by the observer. Families and professionals often expressed negative perceptions of repetitive behaviours. It was not possible to reach an exhaustive list of autistic repetitive behaviours because of the unlimited, personally meaningful ways of behaving in response to changing demands, judgments, and responses to repetitive behaviours across contexts. Personal perspectives suggested that all repetitive behaviours served a meaningful function. There were intrinsic benefits of

repetitive behaviours for autistic young people, and further benefits to whole families when there was a shared appreciation of everyday demands. Repetitive behaviours allowed negative experiences to be lessened, and positive experiences to be increased.

Discussion

This constructivist grounded theory review presents a description of autistic repetitive behaviours that is based on the perspectives of autistic young people, their families, and supporting professionals. This is as follows: repetitive behaviours are prioritised by autistic people in response to their environments because they serve many meaningful functions that reduce social, sensory, and flexible thinking demands. Their use can contribute to autistic people feeling content in the world. The degree to which repetitive behaviours are problematised, accepted, or celebrated depends on the subjective interpretation of the person observing the behaviour. This reflects the social context of any “disability” (Kapp et al., 2013).

The neurodiversity paradigm outlines the premise of social acceptance of difference and the desire to seek interventions that enhance quality of life for autistic individuals (Dwyer, 2022; Pellicano & den Houting, 2022). This contrasts with a variety of approaches that attempt to change behaviours without appropriately considering the autistic person’s viewpoint, such as applied behavioural analysis, which have been robustly criticised (Bottema-Beutel & Crowley, 2021; Najeeb & Quadt, 2024; Pellicano & den Houting, 2022; Pukki et al., 2022). The conceptual summary presented in this review describes the functions, or meaningfulness, of “restricted, repetitive patterns of behaviour, interests, or activities” (APA, 2022; NICE, 2017; WHO, 2022). The review concludes that repetitive behaviours shown by autistic young people reflect the amount of demand within their environments. Repetitive behaviours reduced cognitive demands by providing reprieve from worrying. Examples of repetitive behaviours included listening to familiar music, reading familiar books, or breathing mindfully. A theoretical understanding of flow states can help to understand some repetitive behaviours used by autistic people. A “momentum of thought” or “difficulty starting, stopping or changing direction” have been described as inertia or flow states (McDonnell & Milton, 2014; Murray, 2018), which may underpin some of the immersive activities described. Additionally, there were descriptions that young people used repetitive behaviours to respond to flexible thinking demands, to make sense of things that had already happened, or prepare ahead of new situations. In previous literature, roleplaying and storytelling have been said to provide these benefits for autistic people (Fein, 2015). Additional

examples of repetitive behaviours included autistic young people asking questions, making lists, or replaying scenarios from the day. These behaviours were not inherently unusual, rigid, or excessive, but were used as needed. Selecting preferred clothing or foods, fidgeting, or making drumming movements were ways in which autistic young people responded positively to sensory demands and managed their energy levels, to achieve the right level of stimulation or noise. Similar meanings of repetitive body movements have been described by autistic people in previous research (Joyce et al., 2017; Kapp et al., 2013; Petty & Ellis, 2024). Kapp et al. (2019) described the ways in which autistic adults have reclaimed “stimming”; they explained how self-regulatory movements could receive increased social acceptance when they were understood as being an adaptive mechanism. Kapp et al.’s discussion of stimming as a self-regulatory mechanism for autistic adults emphasises both the need to modify overwhelming environments and to destigmatise repetitive behaviours.

In this review, repetitive behaviours were also shown to facilitate belonging and connection with others by providing a shared interest to come together over, or to provide a focus when talking. Online settings and gaming are known to provide particularly supportive contexts for communication, sharing of interests, and welcome of neurodivergent expression for autistic people (Fein, 2015; Gillespie-Lynch et al., 2014). Testimony from autistic people, therefore, provides alternative explanations for “unusual behaviours” that can receive negative judgment, such as communication differences that can be mistaken for low social interest (Jaswal & Akhtar, 2019). This expanded definition of autistic repetitive behaviours provides a companion to diagnostic decision making.

Autism is diagnosed by evidencing deficit-based descriptions of behaviours related to social communication and restricted and repetitive behaviours (APA, 2022; Gillespie-Lynch et al., 2017); these ambiguous criteria remain an essential standard of clinical diagnosis. The variable appearances of repetitive behaviours can help to explain the widely variable rates of diagnosis for autistic people (Crane et al., 2016), and the many accounts from autistic people saying that their behaviours have been misunderstood or omitted from descriptions of being autistic (Griffith et al., 2012; Harmens et al., 2022; Hull et al., 2020; Lever & Geurts, 2016; Stagg & Belcher, 2019). Personal accounts written by autistic authors have long offered a different understanding of autistic behaviours from medical literature (for example, Grandin, 1984; Murray, 2018; McDonnell & Milton, 2014). Practitioners must be aware that if definitions are changing with personal advocacy and emerging research, as illustrated by the findings of this review, but diagnostic criteria are not, autistic people will likely be excluded from fair assessment and support provision. This study offers an aid to clinical

assessment and the design of therapeutic interventions to support autistic people. Clinicians must interpret assessment tools with understanding provided from the personal expertise of autistic people (Fletcher-Watson, 2024; Kapp et al., 2013). This is more helpful than looking for a shortlist of illustrative behaviours.

“Much of autistic behaviour can be seen as attempts to restore some kind of equilibrium” (Murray, 2018). Repetitive behaviours have been explained by autistic authors as being coherent and understandable actions, which contribute to their wellbeing (McDonnell & Milton, 2014; Murray, 2018). This review supports the perspective that repetitive behaviours are a personally meaningful wellbeing resource. Given this understanding, repetitive behaviours shown by autistic young people will vary in their visibility over places and time. For example, parents and autistic young people report more repetitive behaviours when a young person feels anxious (Bearss et al., 2016; Joyce et al., 2017). Autistic repetitive behaviours indicate something important about an individual’s fit in a demanding context, with appreciation of what can be demanding in neuro-majority settings (Botha et al., 2022). This conceptual understanding should inform the design of interventions to support autistic young people. Repetitive behaviours can bring immediate benefits of increased contentment and positive self-identity, which can take precedence over some tasks of daily life, such as preparing to leave the house on a busy morning or sharing mealtimes. Research should seek to understand behaviours before evaluating interventions that prevent or change them (Tural Hesapcioglu et al., 2020). To do so, researchers need to address conflicting interests with autistic people (Bottema-Beutel & Crowley, 2021; Pukki et al., 2022; Sonuga-Barke, 2023). Unconscious bias and its contribution to autism stigma have been explored in research and have been shown to alter how autistic young people are supported (Turnock et al., 2022). The constructivist method used in this study allowed for contradicting assumptions held by autistic young people, their families, and professionals to be reconciled with a whole story understanding of how autistic repetitive behaviours can be described (Charmaz, 2014). Multidisciplinary approaches should be combined to support autistic individuals and their families (NICE, 2017); however, behaviours should not be changed for the purpose of helping autistic young people to look or ‘be’ less autistic (Pukki et al., 2022). Isolation, reduced attainment, and emotional dysregulation (Van Hees et al., 2015) are likely unintended consequences for young people when their behaviours are judged negatively and denied (Cage et al., 2019; Humphrey & Hebron, 2015). Clinicians and researchers must recognise meaningful autistic behaviours and autistic strengths (Pellicano & den Houting, 2022) and the long-term implications of denying autistic expression (Najeeb & Quadat,

2024). Acceptance of the value of repetitive behaviours provides an alternative ambition to censoring them (Kapp et al., 2019).

These findings do not detract from the many ways in which families can be affected when supporting an autistic young person (Burnham Riosa et al., 2023; Nicholas et al., 2016). Low understanding of autism can cause family members to seek knowledge and advice wherever it is available (Anderson et al., 2020; Crane et al., 2016). This review increases the visibility of the assumptions made about repetitive behaviours across different personal and professional contexts. Increased understanding of the meanings of all repetitive behaviours (Bishop et al., 2013), as expanded in this review, should support improved acceptance of difference. This could inform the post-diagnostic information and support provided to families of autistic people. Shared appreciation that daily life is demanding and can contribute to feelings of anxiety and overwhelm provides a different starting point from which wellbeing can be supported (Daly et al., 2022).

Limitations

Most of the studies in this review heard about the experiences of autistic young people from other people, and they missed methodological details of the assumptions and biases underpinning this representation. This limits the extent of personal perspectives heard. Future research should follow guidance for conducting research with autistic people (Fletcher-Watson et al., 2019) and show reflexivity to acknowledge subjectivity and positionality in how research is conducted and reported (Olmos-Vega et al., 2023). Future reviews should also expand the inclusion criteria. This review represented only some autistic people and notably excluded people who had co-occurring neurodivergence or learning disability diagnoses. The findings of this review are also limited by the demographics of the autistic young people represented in the available research. Grey literature was not included in the synthesis and should be reviewed given its inclusion of different viewpoints (Farace & Schöpfel, 2010; Heath et al., 2022).

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Data Availability The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Conflict of Interest The authors declare no competing interests.

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