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Behaviours that challenge in adults with intellectual disability: overview of assessment and management

ARTICLE

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SUMMARY

Up to a fifth of people with intellectual disabilities display challenging behaviour that has a significant impact on their health and quality of life. Psychotropic medication does not appear to confer any clinical benefits beyond risk reduction in acute situations. However, very few non-pharmacological treatments have clear evidence of clinical and cost-effectiveness and there is therefore often a dearth of advice as to which components or interventions would be helpful. To our knowledge no single model has been developed to provide a clear path from understanding the behaviour to the implementation of a therapeutic approach for such a complex clinical problem. In this article we describe a stepped-care model that needs to be further operationalised in the assessment and management of behaviours that challenge in adults with intellectual disabilities.

LEARNING OBJECTIVES

After reading this article you will be able to:

- understand the complexities associated with the treatment of behaviours that challenge in adults with intellectual disabilities
- consider the relative importance of non-pharmacological approaches to the management of behaviours that challenge in adults with intellectual disabilities
- describe a stepped and structured approach to the management of behaviours that challenge in this population.

KEYWORDS

Behaviours that challenge; intellectual disabilities; interventions; psychosocial; formulation.

Behaviours that challenge (challenging behaviour) are a significant clinical problem in the field of intellectual disabilities. Prevalence rates indicate their presence in almost a fifth of people with intellectual disabilities and that different types of such behaviour often coexist, for example aggression towards others together with self-injury or stereotypy (Crocker 2006; Bowring 2017). The most common definition identifies the behaviour as challenging to those who support or come into contact with the individual and recognises that it may be a means of communicating unmet need and can result from an interaction between factors that are intrinsic and extrinsic to the individual, the latter including systems of provision of care (Emerson 2001).

Risk factors associated with the display of behaviours that challenge include severe intellectual disability, autism, communication deficits, demographics such as male gender, and physical conditions such as epilepsy. Severe intellectual disability is mostly associated with self-injury and stereotypies, whereas male gender is mostly associated with outwardly directed aggression (Crocker 2014; Visser 2015).

People with intellectual disabilities who display challenging behaviour suffer a number of poor outcomes, including physical health problems, increased risk of hospital admissions and increased use of restrictive practices (Emerson 2011; Lloyd 2014). As many as two-thirds are prescribed psychotropic medication, especially sedatives, antipsychotics and antidepressants (Hassiotis 2018). Prescribing rates have varied over time, with antidepressants currently being the most prescribed psychotropic although it is unclear whether this is for their primary indication of treating affective disorders (Sheehan 2015; Branford 2022). Despite evidence that pharmacological interventions on their own may do little to reduce behaviours that challenge, they are often seen as the first or necessary option in cases of elevated risk during a crisis and are commonly prescribed for the management of irritability, hyperactivity or aggression in autism spectrum disorders in children (McQuire 2015). The evidence in adults is equivocal, mainly due to the lack of good-quality randomised controlled trials of pharmacological treatments. In the UK, many parents of people with intellectual disabilities, along with clinicians and public bodies, have been advocating for reducing the use of psychotropic medication for challenging behaviour through national initiatives such as audits of prescribing practices and the STOMP–STAMP campaign ('stopping the over-medication of people with a

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learning disability, autism or both' and 'supporting treatment and appropriate medication in paediatrics'; NHS England 2019). It is recognised that medication side-effects and the multimorbidity and polypharmacy that is often seen in vulnerable populations such as people with intellectual disabilities can be detrimental to their overall health and well-being and that non-pharmacological approaches must be made available. To address this global concern and to optimise psychotropic prescribing, professionals, academics and experts by experience have produced clinical guidelines aimed at clinicians and oversight organisations to ensure high care standards in this area (Colwill 2019; National Centre for START Services 2020).

The National Institute for Health and Care Excellence (NICE) in England, and similar organisations in other countries, have produced guidelines to support the assessment and management of challenging behaviours in both residential and community settings, with an emphasis on psychosocial approaches. NICE guideline NG11 (NICE 2015a) includes specific recommendations about the structure of care to be delivered to people with intellectual disabilities and promotes a holistic understanding of behaviours that challenge. The guideline makes specific mention of functional assessment of behaviour, preventive strategies, interventions for family carers and the use of behaviour support plans. For adults, there is special reference to interventions based on behavioural management and to cognitive–behavioural therapy (CBT) for anger management. Other modalities include provision of structured daytime activities and sensory interventions (it is important to establish the person's sensory profile before offering sensory interventions). The guideline also cautiously suggests that medication, if needed, should not be used exclusively but in combination with psychological approaches and that it should be reviewed within 6 weeks of treatment commencing. Quality standard QS101 (NICE 2015b) identifies 12 quality standards (statements) that refer to person- and service-related care elements. These statements are developed in such a way as to allow the measurement of progress against the standard, for example through audit.

One of the principal challenges in developing the NICE guideline was the lack of high-quality randomised controlled trials that could inform the recommendations on which psychological interventions to use, especially in adults. In the intervening years, there has not only been an increase in the number of randomised controlled trials of psychosocial (also called complex: Skivington 2021) interventions for behaviours that challenge but there has also begun a debate about the need for increasing the range of approaches to incorporate current understanding of the multiple underpinning aetiologies of such behaviours, which range from neurocognitive to environmental to emotional to whole systems. Thus, single interventions may be less effective in the face of multiple interactions and comorbidities in this population. As Woodcock & Blackwell (2020) argue 'existing approaches have not provided the whole solution for everyone'.

Assessment and formulation

Identifying the cause behind a display of challenging behaviour can be difficult as the clinician must establish a change from the person's usual behaviour and often can only rely on carers' reports, which can be inconsistent. Furthermore, presentations of mental illness may be atypical, especially in adults with more severe intellectual disabilities, and therefore an accurate description of sustained changes in sleep or appetite (indicating at least moderate depression) may not be available. Research in other mental disorders (e.g. dementia) has identified several frameworks that may be used to provide a holistic conceptualisation of behaviours that challenge: for example, the 'unmet needs' framework (Cohen-Mansfield 2013) theorises that the person is trying to communicate a need or a distressed emotional state. Unfortunately, diagnostic overshadowing, whereby behaviour is attributed solely to the intellectual disability rather than to a treatable cause, still occurs. This can lead to delayed diagnosis of an underlying physical or mental health condition and, on occasion, to death (Ali 2008).

Case formulation

Given the diagnostic challenges, careful case formulation is key in the assessment of an individual who displays challenging behaviour. Formulation allows professionals in a clinical situation to generate hypotheses about the onset, maintenance and resolution of psychological problems in a particular patient. Ultimately, the formulation leads to the delivery of interventions and further revisions of the original formulation.

Although there are different understandings of this process, Sidhu (2020) defined formulation as professionals 'making sense of a person's life, by thinking through their problems, how they might have developed in the first place and what keeps them going'. Therefore, some aspect of formulation is part of every assessment of challenging behaviour. Formulation can be done informally or using frameworks such as the 'five Ps' (presenting problems, and predisposing, precipitating, perpetuating and protective factors; Ingham 2008). Formulation can be done by an individual or a team and may be

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used to identify unmet need; several versions of the approach may be in operation in a service specific to a professional group.

Team formulations are particularly valuable in intellectual disabilities as they involve the collaborative construction of a formulation by the whole team working with the individual (Hymers 2021). Involving the multidisciplinary team and utilising a biopsychosocial approach in these formulations is vital in order to integrate different strands of information. A systematic review (Geach 2018) included 11 articles on the use of team formulations to develop treatment plans for people with intellectual disabilities. It identified three types of practice that could be defined as team formulation: 'highly structured consultation, reflective practice meetings and informal sharing of ideas'.

Team formulations have also been used to enhance the patient's contribution to care planning, through networks such as quality improvement programmes. One in-patient service for people with intellectual disabilities (Rowe 2014) encouraged patient input in multidisciplinary team formulations using the biopsychosocial model, although it acknowledged the significant resource implications required to achieve this aim. A pilot evaluation of workshops teaching direct care staff to use biopsychosocial formulation to understand and respond to challenging behaviour displayed by people with intellectual disabilities reported that multidisciplinary team formulations had positive outcomes for both staff and the individuals in their care (Ingham 2008). Staff on one in-patient unit for people with intellectual disabilities reported that team formulation helped them to gain greater understanding of their patients (Turner 2018), although staff on another such unit said that 'poor communication and interaction and inconsistent staff attendance' hindered team formulation meetings (Hymers 2021). Ingham et al (2020) have recently described the psychometric properties of the Formulation Understanding Measure, which evaluates team formulations constructed by direct care staff in intellectual disabilities services.

However, as is the case in other fields, there is a poor description of harms resulting from use of the team formulation model or of the outcomes that could be directly linked to it (Geach 2018). It has been argued that formulations can be resource intensive, require training in order to be delivered effectively and are not always necessary (James 2021). There is no universally agreed perspective on what should and should not be included in the process of constructing a formulation, and a systematic review (Holle 2017) of individualised formulation-led care failed to identify one that is superior to the others.

Stepped care

Taking together the existing literature, we argue that current stepped-care models can foster inconsistency in practice which has consequences for the care of people with intellectual disabilities. We propose that a revised paradigm of the care pathway for the assessment and management of behaviours that challenge may avoid some of the limitations of the models currently in use. Although obtaining in-depth information about a person is an important step in the care pathway, it must be balanced with the provision of actions and strategies that will ultimately demonstrate improved outcomes.

The assessment of a person with an intellectual disability who displays behaviours that challenge has two objectives: first, to help the person and/or family or direct care staff to cope with the behaviour; and second, to replace the challenging behaviour with prosocial behaviour via the delivery of non-pharmacological interventions (Hastings 2010).

Stepped care is a useful structured way in which to tailor formulations and hence interventions to the efficient management of the presenting complaint. Multidisciplinary team formulations utilising a biopsychosocial approach usually require skilled practitioners to construct and implement them. Therefore, it stands to reason that there should be a tiered route to these more intensive supports, depending on the nature and severity of the presentation. Furthermore, such an approach is arguably more helpful in the case of a disorder that remits and relapses over time.

The stepped-care model

Figure 1 outlines our proposed stepped-care model for the assessment and management of challenging behaviour. As indicated by the double headed arrow, the model may not function in an entirely linear way and individuals with complex presentations may go up or down the steps and even skip steps. Behaviours that challenge can become chronic if not addressed effectively and efficiently. Therefore, if there is no response at lower stages in the model, it is important to move up to the next stage.

Step 1

Behaviours that pose very low risk of harm to the person or others (including to physical health and general well-being) may require little or no action from family carers or direct care staff. Such behaviours could be tolerated while various factors that might precipitate their onset are explored. Common problems that should be excluded early on include pain, side-effects of medication, pre-existing or emerging mental illness, constipation and

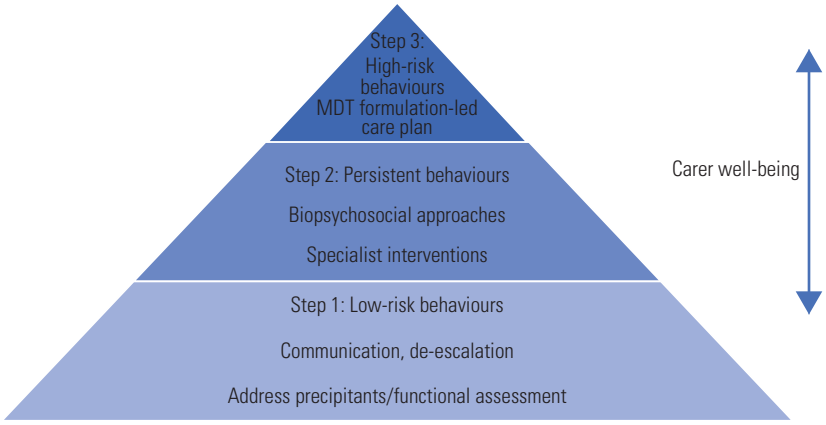

FIG 1 A stepped-care approach for managing behaviours that challenge. MDT, multidisciplinary team.

delirium. It is advisable for direct care staff or family carers to raise concerns with the health teams the person is registered with, who will advise on next steps and facilitate, if needed, contact with a general practitioner (GP) for screening or review.

After any immediate concerns have been addressed, it is important to use low-intensity interventions such as functional assessment to understand the reasons for the behaviour. Functional assessment of challenging behaviour is used with many populations, including those without intellectual disabilities, to identify the cause of the behaviour and develop hypotheses that are then tested to find a solution. It comprises the collection of data from direct observations of the individual and from carers, followed by functional analysis. The latter assumes that the behaviour has one of four functions: to gain attention from a social or care network; to escape/avoid a situation, person or activity; to obtain/achieve a preferred object or activity; or to fulfil a sensory need (Cooper 2014).

Non-specialist health professionals can be trained to carry out these assessments with a view to developing a positive behaviour support (PBS) plan that guides carers to focus on areas of change which are likely to improve communication between family, the person, care staff and professionals. This may include development of joint understanding of the person's preferences and personal history, improvements in the physical environment, finding new occupational opportunities and anticipation of times when behaviours that challenge may be more likely to occur, such as when personal care is being given.

The well-being and resilience of family carers and direct care staff should also be addressed, with the attention on gradually building competencies that aid both the management (reactive) and prevention of behaviours that challenge. Competencies must include the use of basic de-escalation skills and the assessment of triggers, especially for aggressive behaviour. Basic de-escalation skills may overlap with, and can be supplemented by, distraction or delaying techniques depending on the level of the person's intellectual disability. In many cases, this may be enough to resolve an episode (Inglis 2013). Tools to help anticipate and plan for managing risk due to aggressive behaviour have been tested in mental health facilities and also in community settings and emergency departments (Hassiotis 2022).

Step 2

If those initial strategies do not reduce or eliminate the behaviour or risk is increasing, the next step is to turn to manualised interventions that are carried out by trained clinicians. A number of interventions have been adapted or developed for behaviours that challenge in people with intellectual disabilities (Box 1). These range from the more common therapies such as CBT and mindfulness to intensive interventions to enhance communication in people with more severe cognitive limitations. More recently, there has been interest in the utilisation of eye-movement desensitisation and reprocessing (EMDR) in the treatment of challenging behaviours in adults with intellectual disabilities who have experienced trauma (Karatzias 2019). These interventions, when available, are usually delivered by professionals from specialist community intellectual disability services or mental health services through locally agreed clinical pathways such as NHS England's Improving Access to Psychological Therapies programme. This step also includes various evidence-based approaches along the biopsychosocial spectrum, such as improving physical health, exercise and activity regimes, social interaction and the use of regular systematic medication reviews to optimise prescription and administration of medication (National Institute for Health and Care Research 2020).

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BOX 1 Single interventions for behaviours that challenge in adults with intellectual disabilities

- Group cognitive–behavioural therapy (CBT) for anger management (Willner 2013)[a]
- Dialectical behaviour therapy (Sakdalan 2010)
- Mindfulness-informed approaches (Griffith 2016), including hybrid interventions such as mindfulness-based CBT (Singh 2008) and mindfulness-based positive behaviour support (Singh 2019)
- Who's Challenging Who? (Hastings 2018)[a]
- Steps to effective problem-solving (STEPS) (Ailey 2018)[a]
- Staff training in positive behaviour support (Hassiotis 2018; McGill 2018)[a]
- Eye-movement desensitisation and reprocessing (EMDR) (Karatzias 2019)

a. There is at least one adequately powered randomised controlled trial of clinical and/or cost-effectiveness

BOX 2 Management of behaviours that challenge: what should be included in a service pathway

- Set the objectives (who to work with; prevention or treatment only?)
- New referrals and crisis management
- Initial assessment (who will complete it) and risk assessment
- Outcome of initial screening: if referral to the pathway is agreed in multidisciplinary discussion, decide on allocation of care coordinator(s), plan for assessment and interventions, establish the degree of urgency and level of risk
- Those on the pathway will receive profession-specific input (e.g. professionals trained in positive behaviour support, speech and language therapy, occupational therapy, psychiatric review, nursing, social work) and network involvement (e.g. carer education and monitoring plan)
- Use of outcome measures (e.g. Behavior Problems Inventory) and multidisciplinary/multi-agency reviews
- If progress is satisfactory, decide whether to discharge, taking into consideration carer and patient feedback on the experience
- Contact with care coordinator 6 months after discharge

Step 3

The final step is for the most high-risk situations or individuals who have not responded to steps 1 and 2. These cases are likely to require an in-depth multidisciplinary team formulation for a more detailed understanding of the underlying problems and conceptualisation of the intervention that may be needed within a formulation-led care plan. In the most serious cases it is likely that clinicians may need to consider the option of psychiatric inpatient admission or of alternatives such as crisis team intervention or respite care.

An important part of the assessment and management of challenging behaviour is the psychological well-being of family and paid carers. There is evidence to show that family carers living with children who display behaviours that challenge can experience psychological harm (Flynn 2018). However, the authors conclude that the evidence for the impact of particularly aggressive challenging behaviour on paid carers' psychological well-being is equivocal, with some studies showing an association and others not. Therefore, we propose that the assessment should include a discussion of the carers' psychological well-being and that simple advice and resources be made available where there appear to be concerns raised.

Interventions, outcome measurement and service delivery

Psychosocial and pharmacological treatments are discussed in our previous article in *BJPsych Advances* (Ali 2014). During all of the proposed steps in the model, materials to monitor the effect of interventions and symptom trajectories should be used to support personalised care.

Box 2 outlines elements of a pathway for the management of behaviours that challenge as an example of care currently provided in one intellectual disabilities service in England (Camden Learning Disabilities Service). The pathway is multidisciplinary, led by staff trained as positive behaviour support coaches and includes regular basic training in behavioural principles of all service staff as a minimum.

In 2020 we identified 80 intensive support teams in England which follow an enhanced or independent care model for adults with intellectual disability and behaviours that challenge (Hassiotis 2020). Although these do not usually manage crises arising from such behaviour they may have a role to play within community intellectual disabilities services. They could complement the clinical pathway, providing an enhanced response to persistent behaviours and would fit at step 2 or 3 depending on local operational policies.

MCQ answers
1 d 2 a 3 b 4 a 5 e

Conclusions

The stepped-care model described in this article follows evidence and best practice found in many different guidelines and used by the majority of clinicians, although there is variation across services. Since the publication of NICE guidelines on interventions for challenging behaviour in people with intellectual disabilities (NICE 2015a), there is cautious optimism generated by emerging directions in understanding the underlying aetiologies of such behaviour and the relative proliferation of adapted or newly developed psychosocial therapies for its management.

However, clear evidence drawn from large randomised controlled trials is still lacking and the health economic evaluation of psychological interventions in the field of intellectual disabilities is in its infancy, with only a few studies including such approaches (Hunter 2020). Both of those are necessary conditions for the rollout of the interventions in intellectual disabilities services in the NHS and beyond. Good-quality evidence is pivotal in offering interventions that work in practice, are cost-effective and do not cause harm. Although behavioural approaches are the mainstay of management of behaviours that challenge, they fail in a significant minority of cases. As multiple comorbid conditions contribute to the complexity of the display of such behaviours this should also be reflected in the treatment approaches used; one such is the standardised delivery of care alongside a multimodal and multicomponent perspective using a logical needs-led formulation and, most importantly, specific intervention options.

We have outlined here a revised approach to the concepts of assessment and management of challenging behaviours drawing from existing and emerging evidence utilising a variety of concepts, some outside the field of intellectual disabilities. We propose a framework that, if further developed, could lead to a more efficient tailoring of resources and skills to address behaviours that challenge and improve the lives of people with intellectual disabilities and their family carers.

We have not discussed the management of behaviours that challenge in individuals with autism spectrum disorders. Overall, for adults with coexisting intellectual disabilities and autism, challenging behaviour appears to correlate with the severity of autism symptoms and intellectual disability (McCarthy 2010). Although principles of management as described in this article may apply, more autism-specific interventions will be required that are tailored to underpinning processes such as physiological hyper- or hypoarousal (McDonnell 2015). The National Autistic Society in the UK has produced guidance to support carers (National Autistic Society 2020). However, the management of behaviours that challenge in people with autism without intellectual disabilities is outside the remit of this work and merits separate consideration.

Author contributions

A.H. accepted the invitation, prepared the first draft and contributed to the revised versions of this article. H.R. contributed to the content and all revised versions. Both agreed on the submitted version.

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Declaration of interest

None.

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MCQs

Select the best single option for each question stem

1 NICE guidelines on the management of behaviours that challenge in adults with intellectual disabilities recommend that antipsychotics:
- a are first-line treatment
- b are preferable to antidepressants
- c must never be used
- d must be reviewed around 6 weeks from commencing treatment
- e must not be combined with psychological treatments.

2 The initial management of low-risk behaviour in the stepped-care approach for managing challenging behaviour does not include:
- a cognitive–behavioural therapy
- b distraction techniques
- c physical health review
- d review of medication side-effects
- e verbal de-escalation.

3 The stepped-care model for managing challenging behaviour:
- a advises paid carers about stopping psychotropic medication
- b includes a treatment plan of interventions based on severity of behaviours
- c cannot be used in family homes
- d uses a traffic light system to indicate risk level
- e uses theory of behaviour change.

4 A clinical formulation:
- a can be used by professional teams to better understand the presenting complaint
- b cannot be used in the care of people with intellectual disabilities
- c does not include patient perspectives
- d must only be used by psychologists
- e must be used at all times before developing a treatment plan.

5 A service pathway for the management of behaviours that challenge may include:
- a care coordination
- b initial screening and assessment
- c multidisciplinary reviews
- d an explicit statement of key objectives
- e all of the above.