Intellectual Disability (ID)

Behavioural Issues in Intellectual Disability
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Aims and Objectives (from handbook)

- Understanding challenging behaviour and awareness of methods of recording/assessing
- Aetiology of challenging behaviours
- Management options
Behavioural Issues in ID

To achieve this

• Case Presentation
• Journal Club
• 555 Presentation
• Expert-Led Session
• MCQs

• Please sign the register and complete the feedback
Behavioural Issues in Intellectual Disability

Expert Led Session

Intellectual Disability and Challenging Behaviour
Dr Olutu
Behavioural Issues in ID

• Be able to define challenging behaviour (CB) in mental health/intellectual disability
• Understand of the different types of challenging behaviour
• Gain a knowledge of the causes of, and maintaining factors for challenging behaviour
• Understand the behavioural, psychological & pharmacological approaches to managing patients with challenging behaviour.
Epidemiology

According to a report produced by Mansell

- Estimates depend on definitions,

- It is likely that about 24 adults with a intellectual disability per 100,000 total population present a serious challenge.

- There are over 12,000 people with intellectual disability and challenging behaviour in England at any one time.

- Few of these will present such a challenge more or less all the time.

- Many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time.
Challenging Behaviour – concepts 1

• The most widely used, formalised definition has been that of Emerson:
• ‘culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities’.
  (Emerson, 1995)
• The RCPsych have adopted the term challenging behaviour to serve as a reminders that these behaviours should be seen as a challenge to services rather than a manifestation of psychopathological processes
• challenging behaviour is a socially determined concept and should not be misused as a diagnostic label.
Challenging Behaviour – concept 2

• The RCPsych have adopted a modified definition that builds on that of Emerson:

➢ Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.

Challenging Behaviour: a unified approach - Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices – Royal College of Psychiatrists, BPS and RCSALT - College Report CR144, June 2007
Implications of new definition

Thus the prevalence of challenging behaviour can be conceptualised within such parameters as:

- No. of individuals excluded from local services
- No. of individuals in ‘out of area’ placements
- No. of individuals not receiving day services, employment
- Opportunities, education, respite or home support
- Service responses involving
  - Seclusion; restraint; locked doors; abuse
- Clinical responses involving
  - Inappropriate prescribing of drug treatments; punitive and aversive behavioural interventions; risk avoidance rather than risk management\textsuperscript{1,2}
Case Scenario

*Paul is a 25 year old man with mild intellectual disability living with James in supported accommodation.

*Every time Sarah (carer) attends to James, Paul starts hitting the walls and shouts
Aetiological Factors

* Physical: discomfort, pain, malaise, physiological disturbance (e.g. Thyroid disorders)
* Mental illness: Mood disorders, psychosis, anxiety, OCD
* Neuropsychiatric disorders: Epilepsy, Gilles de la Tourette syndrome, attention-deficit hyperactivity disorder (ADHD), dementia
* Pervasive developmental disorders: autism
* Phenotype-related behaviours: Prader-Willi syndrome, Lesch-Nyhan syndrome, Williams syndrome
* Psychological trauma: reaction to abuse or loss
* Communication difficulties: Hearing loss, unclear communication, insufficient vocabulary or means of expression, difficulties understanding communication of others
*3 Elements need to be considered (Diagram above)

*Individual factors:
  * Degree and nature of intellectual disability; Sensory or motor disabilities; Mental health problems; Physical problems, including pain and/or discomfort; Communication difficulties, personal history of relationships and experiences.

*Environmental factors will include the characteristics of services:
  * Number of staff; Training and experience of staff; Consistency of staff provision and approach; The working relationship with the client; Working relationship between staff; Quality of the material environment; Opportunities available; Ability of the service to understand and respond to unique needs of individuals

*A poor fit between the individual’s needs and their environment may result in limited opportunities to:
  * Gain social attention; Escape from or avoid excessive demands; Gain access to preferred activities or objects; Gain alternative forms of sensory feedback; Reduce arousal and anxiety by other means; Exert choice or control over environment; Understand and communicate with the person.
**Purpose:**
- Collect enough information to lead to a coherent formulation or diagnosis
- Lead to an intervention plan which fits the person and their environment, and leads to an improvement in their quality of life
- Establish a baseline that enables subsequent evaluation of effectiveness.

**Focus of the assessment:**
- Determined by the impact of the behaviour on the individual and those around them
- Degree of physical harm to the person and others
- Risk of loss of access to opportunities for development and participation
- Levels of distress being experienced by the person and others
- Capacity and motivation for change in the person and in their environment
Pre-assessment information should include:

- Descriptions of the challenging behaviour
- Circumstances in which the behaviour occurs
- Frequency and severity of the behaviour
- Sensory impairments
- Person’s communication style
- Communication typically used by other people
- Specific disabilities, including aetiology of intellectual impairment
- Medical problems
- Current medication
- Setting in which the person lives/works
- Previous interventions
- Risks to the person or to others
- Existing risk management strategies
- Capacity to consent to current and potential interventions.
Assessment – 3

Assessment of risk

Part of the preliminary assessment and should include:

1. Description of the behaviours (frequency, duration and intensity) and as well as who or what is at risk

2. Identification of any warning signs or triggers displayed by the individual that may indicate the probability of escalation of risk

3. Identification of aspects of the environment that are associated with increased likelihood of the behaviour.
Three key dimensions:

• Frequency - How often it occurs (e.g. rate per hour/day)

• Duration - How long it lasts

• Intensity - How serious it is (a qualitative judgement)
Measuring Behaviour – 2

Hand biting
Kicking
Punching

9-10am  10-11am  11-12pm  12-1pm  1-2pm
Assessing Behaviour – 1

*The ABC model of behaviour:
  * Antecedent - Observable events happening before the behaviour being assessed occurs.
  * Behaviour - The behaviour being assessed.
  * Consequence - Observable events happening after the assessed behaviour occurs.
*Used for low frequency behaviours.

*Requires detailed information as soon after the incident as possible.

*Can quite quickly identify common functions for CBs.

*Does not consider the effects of thoughts and feelings on peoples’ behaviour.
Assessment of function of behaviour – 1

*Functional Assessment
*Specific behaviour-analytic procedure, where structured observation and other methods of assessment (interviews or use of standardised questionnaires) are employed to generate hypotheses about the challenging behaviour, antecedents and consequences which may be reinforcing it.

*Functional assessment and functional analysis are used interchangeably by some clinicians.

*Functional assessment - more inclusive term that refers to a range of approaches to establish the function of the behaviour

*Functional analysis - more structured techniques that may include manipulating antecedents and consequences in order to establish their functional relationships (E.g. analogue assessment, Iwata et al, 1990).
Evidence-base supports the use of functional analysis for interventions where the primary focus is the reduction/elimination of severe CBs in people with moderate, severe or profound intellectual disability. (Scotti et al, 1991; Didden et al, 1997; Ager & O’May, 2001).

Functional analysis should follow three stages (Horner, 1994; Repp, 1994; Toogood & Timlin, 1996)

*Stage 1 – hypothesis development¹
*Stage 2 – hypothesis testing²
*Stage 3 – hypothesis refining³
Assessment of Physical Disorders

*The Role of physical disorders should be actively considered and commonly include:
  * Headaches and migraine
  * Cerebrovascular and epilepsy-related events
  * Earache and toothache
  * Eyesight disorders
  * GI related pain: gastro-oesophageal reflux, colic, peptic ulcers and constipation
  * UTI and prostatism
  * Bone and joint pain
  * Neoplasms
  * Wounds and fractures.
Assessment of Psychiatric Disorders

*Xenitidis et al (2001) presented schematically the relationship between challenging behaviour and psychiatric disorders across the spectrum of intellectual ability.
*This indicates that not all people with a intellectual disability will show behaviour that is challenging and vice versa
*Overlap between autism and psychiatric disorder, but neither necessarily leads to behaviour that is challenging
Formulation

*Formulation is best regarded as an hypothesis about the nature of the presenting problem and its development¹.
*It has 2 main functions
  *To guide clinical intervention within an explicit rationale
  *To aid the establishment of criteria for evaluation of the intervention.
*Formulation is a component of both psychological and psychiatric interventions.
*No one single ‘correct’ way to carry out a formulation; method and form will depend upon the context, the theoretical model being utilised, and the particular purpose of the formulation (Harper & Moss, 2003)
*The delivery of individualised support is to be done within a Positive Behaviour Support Framework¹ (Carr et al, 2002)

*Positive behavioural support integrates the following components into a cohesive approach:-
  * Comprehensive lifestyle change; a lifespan perspective; ecological validity; stakeholder participation; social validity; systems change; multi-component intervention; emphasis on prevention; flexibility in scientific practices; multiple theoretical perspectives.
Interventions should be person-centred.
Multi-agency and multidisciplinary involvement should occur in close partnership with families and other carers.
Detailed information concerning the nature and outcome of previous interventions should be obtained and taken into account.
Therapeutic modalities may be delivered in combination (e.g. medication and family therapy). Depending on the findings of the risk assessment described above, the therapeutic interventions may need to take place in an environment in which safety and security can be offered.
Within the positive behavioural support framework plan should include both proactive strategies¹ and reactive plans² (Allen et al, 2005).

Proactive strategies - expected to reduce the frequency, intensity or duration of the challenging behaviour by either

* Adjusting aspects of the environment in order that they are more supportive, or
* Attempting to address individual factors such as skills and tolerances via systematic skills building, or
* Addressing physical health problems via medical intervention.

Reactive strategies - deals with specific incidents

* Early intervention when signs are present that challenging behaviour may be about to occur.³ The aim is to diffuse the situation in to prevent escalation
* Physical management of the individual in order to ensure the safety of all those involved.
Aetiology of challenging behaviour may relate to psychological trauma e.g. past or ongoing history of abuse, losses or bereavement (Hollins & Esterhuyzen, 1997), problems in sexuality and intimate relationships, intra-familial and inter- and/or intra-personal conflict.

CBT¹

Psychodynamic approaches² (Hollins & Sinason, 2000; Beail, 2003; Wilner, 2005).³

Group analytic approach⁴ (Xenitidis, 2005)

Family, systemic or group analytic models⁵
Communication Intervention

*Communication-focused approaches to challenging behaviour reported in the literature (Bradshaw, 1998; Brown, 1998; Chatterton, 1998; Dobson et al, 1999; Thurman, 2001).

*May include interventions to:
  * Increase the communication skills of individual by increasing the effectiveness of existing communication skills¹, teaching more ways of communicating²
  * Increasing skills of the communication partners by improving recognition and understanding, provide appropriate models of communication, use of signs, symbols and objects, in addition to spoken communication
  * Improve the wider communication environment by promoting good listening environments³, providing individuals with opportunities to take part in a range of communication acts⁴ increasing the amount of good quality communication
Positive Programming

*This consists of system where interventions are delivered through mediators skilled in positive manner, organised and supported in a way so they can support individuals positively

*An approach is active support (Jones et al, 1999) includes activity planning, support planning and training for providing effective assistance
Physical/medical Interventions

- Challenging behaviour can be due to an underlying medical condition (e.g. chest infection, dehydration, epilepsy) that requires medication or other physical treatment.

- This should be addressed promptly.
Psychopharmacological interventions

*L*ittle evidence base of it’s effectiveness in CBs

*A*ppropriate form of treatment if underlying cause of challenging behaviour is as a consequence of a mental illness

*M*edication if considered should be an integral part of a comprehensive intervention strategy and should be regarded as adjunctive or complementary to other non-drug interventions planned and delivered by various members of the MDT (Deb et al, 2006)
Prior to initiating medication in discussion with patient, family, carer and MDT the following should be noted

* The range of Mx options that has been considered
* The Medication the patient is already prescribed
* Any past adverse reactions to medication
* Clear rationale for the proposed drug treatment
* Likely effectiveness of the proposed treatment
* Clear, objective method of assessment of outcome and SEs
* Capacity and consent discussed and recorded
* Is Tx in the best interests of the individual?
* Is Tx and its implementation consistent with relevant legal frameworks?
* Is the dose and planned duration of Tx within BNF and other good practice prescribing guidelines and dose recommendations? ¹
Psychopharmacological interventions-3

*Urgent intervention for the protection of the individual or of others may be required.
*Follow established ‘rapid tranquillisation policy’ (NICE 2005) or (Maudsley Prescribing Guidelines - Taylor et al, 2001)
*Modified if necessary to take account of increased vulnerability of people with intellectual disability to adverse effects of medication.
Evaluation

* Ethical obligation to measure the impact of interventions on the target behaviour,
* Routine evaluation for their effectiveness¹
* Repeat baseline measures taken at the start of an intervention and look for any evidence of change.
* As a minimum, evaluation should consider
  * Severity, frequency and duration of the target challenging behaviour
  * Person’s quality of life and range of activities or opportunities
  * Person’s development of positive skills and abilities
  * Person’s well-being and satisfaction with the intervention
  * Well-being and satisfaction of carers or family members in close contact with the person.
* Adverse effects of the intervention should also be carefully monitored.
* Always consider withdrawal of medication if part of overall intervention plan
* Specific evaluation of those factors that he or she is attempting to change.
* Review of the initial formulation.
* Work on relapse prevention²
Key processes associated with using medication to manage behaviour problems in adults with a learning disability:

- Assessment prior to treatment
- Formulation/working hypothesis (includes full consideration of non-medication managements and the rationale for the use of medication)
- Initiation of treatment
- Monitoring of treatment
- Consider withdrawal or continuation

- Feedback and information sharing
- Individual’s/carer’s involvement
- Interdisciplinary working
- Legal framework
- Capacity/consent

- Evaluation of effects and adverse events/quality of life (where possible using objective measures)
1. Causes of challenging behaviour in a person with intellectual disability:
   A. Pain
   B. Overstimulation
   C. Under stimulation
   D. Wanting attention
   E. All of the above
ID – session 3

MCQs- Answers

1. Causes of challenging behaviour in a person with intellectual disability:
   A. Pain
   B. Overstimulation
   C. Under stimulation
   D. Wanting attention
   E. All of the above
2. The following statements are true of factors increasing challenging behaviours in a person with learning disability except which option?

A. Undetected physical illness
B. Communication problems
C. Underlying mental illness
D. Environmental issues
E. Problem solving ability
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A. Undetected physical illness
B. Communication problems
C. Underlying mental illness
D. Environmental issues
E. Problem solving ability
3. Inappropriate behaviours may be maintained by reinforcement from others. Which of the following is a process that helps to identify factors maintaining that behaviour?

A. Functional analysis
B. Statistical analysis
C. Procedural analysis
D. Behavioural analysis
E. Goffman analysis
3. Inappropriatebehaviours may be maintained by reinforcement from others. Which of the following is a process that helps to identify factors maintaining that behaviour?

A. Functional analysis
B. Statistical analysis
C. Procedural analysis
D. Behavioural analysis
E. Goffman analysis
Match each of the following psychological strategies to their possible effects:

A. Proactive Strategies
B. Positive Programming
C. Focused Support
D. Reactive Strategies

1. Systematic instructions given for greater skills and competence development which improves social integration
2. To produce rapid results and reduce reactive strategies
3. Designed to manage the behaviours at the time they occur
4. To produce change over time.
Match each of the following psychological strategies to their possible effects:

A. Proactive Strategies
B. Positive Programming
C. Focused Support
D. Reactive Strategies

1. **Systematic instructions given for greater skills and competence development which improves social integration**-B

2. To produce rapid results and reduce reactive strategies

3. Designed to manage the behaviours at the time they occur

4. To produce change over time.
Match each of the following psychological strategies to their possible effects:

A. Proactive Strategies
B. Positive Programming
C. Focused Support
D. Reactive Strategies

1. Systematic instructions given for greater skills and competence development which improves social integration

2. **To produce rapid results and reduce reactive strategies** - C

3. Designed to manage the behaviours at the time they occur

4. To produce change over time.
Match each of the following psychological strategies to their possible effects:

A. Proactive Strategies
B. Positive Programming
C. Focused Support
D. Reactive Strategies

1. Systematic instructions given for greater skills and competence development which improves social integration
2. To produce rapid results and reduce reactive strategies
3. **Designed to manage the behaviours at the time they occur**-D
4. To produce change over time.
Match each of the following psychological strategies to their possible effects:

A. Proactive Strategies
B. Positive Programming
C. Focused Support
D. Reactive Strategies

1. Systematic instructions given for greater skills and competence development which improves social integration
2. To produce rapid results and reduce reactive strategies
3. Designed to manage the behaviours at the time they occur
4. To produce change over time. - A
Intellectual Disability – session 3

Any Questions?

Thank you.

(please complete the feedback)