How service users with learning disabilities understand challenging behaviour and approaches to managing it

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Rationale

- Challenging behaviour occurs in approx. 10-20% of people with learning disabilities (Allen et al. 2007) and is associated with reduced quality of life (Allen et al., 2007; Murphy, 2009), increased exposure to abusive practices (Emerson et al., 1994), placement breakdown (Allen, 1989) and high staff turnover (Felce et al., 1993).

- Typical interventions focus on environmental management (e.g. ABA, PBS) rather than direct work.

- Much of the research focuses on staff and service level factors which promote effectiveness in managing challenging behaviour.

- Little research capturing service user perspectives on how challenging behaviour is understood and managed.
Rationale

- Enables potential unintended consequences of intervention models to go unnoticed.
- Fails to elucidate the impact of broader service practices on SU understanding of their own behaviour.
- Fails to capture the impact of service user understandings of their behaviour – e.g. on their identity, how they attempt to manage behaviours, well-being, relationships.
- Fails to capture service user perspectives on whether other intervention models could usefully inform their experience of challenging behaviour.
Research Questions

- This study explored:
  - the understandings that service users with learning disabilities and challenging behaviour held around their own behaviour
  - the factors and processes which shaped these understandings
  - the relationship between challenging behaviour, how behaviours are understood and broader well-being.
Method

- 8 participants (6 male, 3 female) with learning disabilities and challenging behaviour took part in individual semi-structured interviews.
- All participants were living in supported residential placements, 7 in secure units and 1 in a community house.
- Presenting challenging behaviour varied but included physical and verbal aggression, self-harm, inappropriate sexual behaviour, property destruction and absconding. Most participants presented with multiple behavioural difficulties.
- Interviews were transcribed and analysed using interpretative phenomenological analysis (IPA)
- Four master themes emerged from the analysis.
Master Theme 1 - Challenging behaviour can be construed at an internal or external level of explanation

- Participants tended to understand their behaviour either in internal terms, as a response to cognitive or emotional processes, or in external terms, as a response to external events.
- Internal understandings
  - were linked to participation in therapeutic groups and to reflective conversations with staff members following incidents.
  - drove cognitive, attentional and self-soothing management strategies.
  - were associated with stronger self-efficacy beliefs around ability to manage challenging behaviour, and a more positive perception of future challenges.
  - However could also have a negative impact on identity (see theme 4)
Master theme 1 continued

- External understandings:
  - were construed as either linear, in which behaviour was viewed as a direct response to an external event, or circular, in which behaviour was viewed as occurring in mutually coercive cycles of interaction.
  - in some participants, were associated with a reliance on staff intervention and environmental management, and resultantly with learned helplessness and passivity.
  - in others – promoted active change strategies (e.g. advocacy, tried to improve peer relationships) which were associated with meaningful systemic change and a greater sense of agency.
Master Theme 2: Positive relationships act as a buffer to challenging behaviour

- **Positive peer relationships:**
  - Provided a safe context in which to learn conflict resolution skills and improved motivation to manage challenging behaviour to reduce its impact on relationships.

- **Positive staff relationships:**
  - Provided a trusting relationship which the individual could draw on for support and guidance.

- **Positive family relationships:**
  - Provided a sense of belonging and experience of relationship roles not characterized by a “looked after” dynamic.
Master Theme 3 - A greater ability to exert power and control in day to day life reduces the frequency of challenging behaviour

- Operated through two mechanisms:
  - Power and trust: Increased freedom was seen as a sign of being trusted and having progress recognized, which then drove motivation to continue to progress.
  - Power and choice: Increased freedom enabled participants to exercise choice in their day to day lives and engage with activities which had meaning for them. This increased well-being and increased the threshold for potential triggers to result in challenging behaviour.
Master Theme 4: The Construction of a Separate Self

- Theme mainly expressed in participants who held an internal understanding of their behaviour difficulties.

- Involved two processes:
  - Suppressing the “challenging self” – not wanting to think about behaviours due to a worry about becoming upset, positioning behaviours in the past, fearing a return to “past self”. Associated with distress.
  - Creation of an alternative sense of self – defined by positive traits, achievements and interests.
Thematic map

Different levels of explanation for challenging behaviour

Facilitators – internal:
- Nurturing context
- Insight groups
- Reflective conversations

Facilitators – external:
- Lack of agency past or current context

Contextual understandings
- Linear
- Circular

Internal understandings – thoughts, emotions, attentional or cognitive processes

Strategies derived with understanding:
- Cognitive, attentional, self-soothing

Without understanding:
- Escape/avoidance

Consequences:
- Self-efficacy
- Positive future predictions

Short-term effectiveness
- Less perceived control

Behavioural incidents

Power and control

Power and trust
- Absent
- Present

Power and choice

Kindling – triggers more likely to result in challenging behaviour

Buffer against triggers resulting in challenging behaviour

Positive relationships buffer against challenging behaviour

Peer
- Conflict resolution
- Increased motivation
- Sense of belonging
- Emotional co-regulation, advice

Family
- Feel safe/understood

Staff
- Advocacy

Construction of a separate self

Suppression of challenging self

Development of an alternative, positive self

Sense of agency

Emotional regulation, advice

Conflict resolution

Advocacy

Feel safe/understood

Long-term systemic change
- Sense of agency

Increased motivation

Passivity
- Learned helplessness
- Constrained future goals

Environment management

Conflict resolution
- Provision of intervention

Advocacy

Long-term systemic change
- Sense of agency

Different levels of explanation for challenging behaviour

Facilitators – internal:
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Facilitators – external:
- Lack of agency past or current context

Consequences:
- Self-confidence
- Positive future predictions

Contextual understandings
- Linear
- Circular

Internal understandings – thoughts, emotions, attentional or cognitive processes

Strategies derived with understanding:
- Cognitive, attentional, self-soothing

Without understanding:
- Escape/avoidance

Consequences:
- Self-confidence
- Positive future predictions

Short-term effectiveness
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Behavioural incidents
Implications

- Recommendations can be tentatively made for different levels of psychological service provision with this group:
  - Direct 1:1 work – opportunities to engage in psychological assessment and formulation to develop a more multi-layered understanding and minimize potentially negative consequences.
  - Support service users to develop a range of change strategies – e.g. small group skills workshops.
  - Organizational level – support development of positive relationships (e.g. through placement planning, staff training, emphasis on facilitating relationships outside of the service) and a positive risk approach.
Limitations

- Findings cannot be assumed to apply to individuals with severe-to-profound ID.
- Heterogeneous group in terms of presenting challenging behaviour and interventions received.
- Additional validity checks would have added rigour.
- Need for converging evidence across multiple methodologies.