

SERVICE USER UNDERSTANDING OF CHALLENGING BEHAVIOR

Title

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

Abstract

Background

This study explored understandings that service-users with intellectual disabilities and challenging behaviour held around their behaviour, what shaped these understandings, and the relationship between how behaviours are managed, and how this relates to well-being.

Method

Eight participants (three female, five male) partook in an individual semi-structured qualitative interview. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results

Three master themes emerged from this analysis; 1) Challenging behaviour can be explained via an internal or external frame of reference, with each framework having different implications for how participants' attempted to manage behaviour. 2) Positive relationships provide a long-term buffer to challenging behaviour, with positive relationships with family, staff and peers operating through different mechanisms to achieve this. 3) A greater ability to exert power and control in day to day life was perceived to reduce challenging behaviour in the long-term.

Conclusions

Implications for practice are discussed.

Keywords: Intellectual disabilities, challenging-behaviour, qualitative

Introduction

Approximately 10-20% of people with intellectual disabilities present with challenging behaviour (Allen, Lowe, Moore & Brophy, 2007), and it is associated with a host of negative outcomes for both people with intellectual disabilities' and those around them (Allen, 1989; Chung, Corbett & Cumella, 1996; Emerson, McGill & Mansell, 1994; Felce, Lowe & Beswick, 1993).

Applied Behavioural Analysis (ABA), which uses principles of behaviourism to target specified difficulties, is the most evidence-based approach to the management of challenging behaviour (National Institute for Clinical Excellence, 2015), with this approach increasingly presented within a Positive Behavioural Support (PBS) model (LaVigna & Willis, 2012). Positive Behaviour Support adopts the methods of ABA, but within an overall value base emphasising increased quality of life and inclusion in valued social roles. PBS also works on the assumption that challenging behaviour represents an attempt to communicate an unmet need, and therefore emphasises the teaching of skills (e.g. communication skills) necessary to provide a functional equivalent to a particular challenging behaviour (Carr et al., 1999; Gore, Hughes, Toogood & Baker, 2013). Interventions provided within a PBS framework are underpinned by a functional assessment. This involves a detailed assessment of the context in which the behaviour occurs, undertaken with a view to developing a better understanding of the need it is meeting. This assessment is most often undertaken through direct behavioural observation, but can also incorporate a range of other methods such as interviews with key stakeholders and ideally will involve direct input from the service-user. Intervention strategies (such as contingency management or skill building) are then devised around this understanding (Gore et al., 2013).. Positive behaviour support (PBS) has demonstrated efficacy in reducing challenging behaviour (Hassiotas et al., 2009; LaVigna & Willis, 2012;). Other, less frequently employed methods of understanding and managing challenging

behaviour include cognitive therapy or skills training groups (e.g. MacMahon et al., 2015; Wilner et al., 2013) and adapted individual therapy with clients (e.g. Willner, 2005). Such methods can also be implemented within an overall PBS model (Gore et al., 2013).

Staff and carer skills, responses to and interpretation of challenging behaviour are known to relate to the effectiveness of interventions for challenging behaviour such as PBS, and, there has been a significant body of research that has focussed on these (e.g. Dagnan, Trower & Smith, 1998; Noone, Jones & Hastings, 2006; Wilcox, Finlay & Edmonds, 2006; Dilworth, Phillips & Rose, 2011; McGill, Bradshaw & Hughes, 2007; Williams, Dagnan, Rodgers & McDowell, 2012). However, the person with an intellectual disability's 'presence' in the challenging behaviour literature has primarily been in the form of quantitative outcome studies using service-user behaviour as a dependant variable (e.g. Allen, 1999; McHale and Carey, 2002; Hatton et al., 2004; Kozma, Mansell & Beadle-Brown, 2009). This is in contrast to the tone of UK policy documents, which advocate for the inclusion of people with intellectual disabilities' in the development of all policy and practice relating to them (Department of Health, 2001). Furthermore, some researchers have identified that failure to capture service-user perspectives can maintain imbalances of power and narratives which legitimize restrictive practices (Nunkoosinga and Haydon-Laurelut, 2011).

Nonetheless, a number of qualitative papers have described the views of people with intellectual disabilities' on aspects of challenging behaviour. A systematic review of the literature (Griffith, Hutchinson & Hastings, 2013) identified 17 papers which focused on people with intellectual disabilities' experiences of challenging behaviour. These papers tended to focus on a particular aspect of challenging behaviour such as self-injurious behaviour (Brown & Beail, 2009), with the majority focusing on experiences of restrictive practices (e.g. Fish & Culshaw, 2005; Hall & Deb, 2008; Harker-Longton and Fish, 2002). Pervasive perceptions of powerlessness was a key theme across these papers, in addition to

the power of relationships in moderating service-user experiences. However, currently no research has directly assessed people with intellectual disabilities' perceptions of their own behaviour, their understanding of the factors and processes that have shaped these perceptions, and the impact of these factors on their quality of life.

The current study therefore aims to elicit detailed descriptions of how people with intellectual disabilities understand their own challenging behaviour, as well as their perceptions of the factors and processes that have shaped these understandings, and the impact of these understandings on their overall well-being.

Method

Design

The study employed a qualitative design, in which data was gathered through semi-structured interviews with service-users who presented with intellectual disabilities and challenging behaviour.

1. Participants

Participants were users of the services of a National Health Service (NHS) Trust in the north of England and a private specialist learning disability service in the Republic of Ireland. None of the authors worked within the participating services at the time the research was conducted. However, the first author had worked within one of the services in the past, and the second author has provided high level consultation to another. No individual who took part in the study was known to the authors in any other context. Individuals were eligible to participate if they were aged 18 or over, currently be in receipt of a intellectual disability service, presenting with challenging behaviour as defined by Emerson (1995), were

able to provide informed consent, and had the necessary language skills to reflect on their experiences. Makaton users were also eligible for participation if the service was able to provide an interpreter.

Eight participants (three female, five male) who ranged in age from twenty-two to fifty-three took part in the study. Presenting challenging behaviour varied across participants, and included physical and verbal aggression, inappropriate sexual behaviour, property destruction, self-harm, and absconding. All participants presented with physical aggression and at least one additional behavioural difficulty, and three participants had previously had restrictions placed on them due to severity of challenging behaviour. All participants lived in supported residential placements, with seven living in residential care units and one in a community house. All participants functioned within the mild to moderate range of ability, thus transferability of the findings to individuals with more severe intellectual disabilities may be limited. Individual demographic information about participants is not presented in order to preserve participant anonymity. Pseudonyms are used throughout.

2. Materials

A semi-structured topic guide was developed in consultation with service-users and was used flexibly to guide the interviews. Topics included perceptions of challenging behaviour more generally, reflections on behavioural difficulties they've experienced themselves, reflections on the causes of these difficulties, reflections on where ideas about their own behaviour have come from, and the influence of these understandings on various elements of quality of life.

3. Procedure

People with intellectual disabilities' were invited to express interest in participating by the staff who worked with them. Data was collected through individual interviews with participants, although four participants requested that a staff member sit with them during the interview. The staff member did not provide any prompts or questions to the participants, but rather were present to help participants feel more comfortable in the interview. Interviews were conducted, audio recorded and transcribed verbatim by the first author.

4. Analysis

Interpretative Phenomenological Analysis was used to analyse the transcribed data, due to its strengths in elucidating both the participants' lived experience and their interpretation of challenging behaviour. In doing so we aimed to gain a more detailed and complex understanding of how people can perceive their own behaviour that can enrich the understandings provided by existing psychological understandings such as the behavioural perspective. Data were analysed according to the Smith & Osborn (2007) process. Each transcript was first read a number of times with a view to familiarisation and the generation of comments or notes on the general essence of the text. Emergent themes were then identified by systematically working through the text, beginning with the first interview. These emergent themes represented a higher level of abstraction than the initial comments, however they retained a close link to the participants' responses. Theoretically consistent emergent themes were then merged to form super-ordinate themes. This process was repeated for the remaining transcripts. The super-ordinate theme list from the first account was used to inform analysis of the subsequent accounts, in order to further articulate these themes and find areas of convergence and divergence in other transcripts. A final set of master themes was then constructed encompassing the super-ordinate themes identified in each transcript.

5. Validity and Reflexivity

The first interview transcript was independently analysed by both the first and last authors in order to increase the validity of the findings. Despite being conducted separate these analyses produced similar initial themes, and when these were discussed it was clear that there was a consensus with regard to the key findings. Subsequent transcripts were analysed primarily by the first author, with consultation with the other authors regarding the emerging themes and their links to the data taking place regularly throughout the analysis process. Themes were continually checked against supporting quotes as they developed in order to maximize validity. The first author is a clinical psychologist with experience working with individuals with learning disabilities and challenging behaviour within a positive behaviour support framework. She ascribes to a critical realist epistemological position, and believes in the efficacy of the positive behaviour support model. . She maintained a reflexive attitude throughout the research, in order to take account of any possible biases to the analysis that may be introduced as a result of the above factors.

Results

Four master themes emerged from the analysis, which are described below. Although there was some variation in how these themes were expressed across participants, each is representative of all participants' experiences.

1. Master Theme 1: Challenging behaviour was understood as occurring due to either internal or external factors, , with different understandings having different implications for how participants' attempted to manage behaviour

The type of understanding that each participant used for their challenging behaviour varied, with some participants understanding their behaviour as a consequence of a series of internal events, and some participants explaining their behaviour as very much responsive to external events with almost no internal mediation. Internal or external understandings had

different implications for how the individual attempted to manage their behaviour.

Furthermore, several service-level factors, including the interventions offered to people with intellectual disabilities, were identified as facilitating the frameworks that individuals' employed in understanding their behaviour.

1.1 Sub-theme 1: Internal understandings of challenging behaviour.

Service-users who employed internal frameworks for understanding their behaviour conceptualized causality for particular incidents as being underpinned by a process of emotions, thoughts, images or memories, and cognitive or attentional processes. Emotions were of crucial importance within this causal chain, identified as important by all participants. Furthermore, many participants identified feelings of sadness, loss or anxiety as precipitating the feelings of anger driving challenging behaviour.

Because they're doing that I feel upset, unhappy and down, and get cross, do things.[...]. I get terrible, bad thoughts. I have stuff like pictures and stuff like that. Black things.[...] They make you feel bad. Then that leads up into an incident (Sarah).

Cognitive processes such as "bottling things up" or rumination were also identified as causing downward spirals in mood and making incidents more likely;

"Sometimes I dwell on it. Then it gets worse and gets me worse in my depression and stuff like that" (Andrew).

Internal understandings of challenging behaviour would appear to be associated with a range of self-initiated management strategies, typically at a cognitive, attentional, or self-soothing level. Self-soothing strategies generally involved providing pleasant sensory input to calm the physical correlates of the strong emotion driving behavioural dysregulation, and included listening to music or a relaxation tape (Alice), squeezing glow-sticks (Heather), or

engaging in a range of activities involving the senses. For example, when asked what helps her to feel calm again, Sarah responded *“Doing your engine changes [...] like tapping your feet, like using your thera-ball, like using your thera-band, like using your body”* (Sarah).

In a similar vein, Alice reported:

“When I feel sad or angry, any music I like, I put it on and it helps” (Alice)

Cognitive strategies typically involved some kind of “slowing down” process, which enabled the individual to sort out their thoughts and feelings, before deciding on a course of action. Some of the participants also described initiating more interpersonal strategies, such as talking through an incident with a staff member, in order to facilitate or further this process;

“Just putting it down helps...I write it down. Just how I feel. [...] It gets it out of your head quicker. And talking quicker” (Alice).

Slowing things down and sorting out thoughts and feelings enabled participants to attempt to come up with alternative solutions:

“I keep doing my problem solving. [...] I go through each bubble and go, “This is what could happen.” So, I solve it in my head and then I’m alright” (Andrew).

When internal self-management strategies were described by participants who predominantly employed an internal understanding of their behavioural difficulties, these individuals appeared to find them of great benefit:

“It (problem solving) helps me a hell of a lot. It helps me feel what a situation is about.” (Andrew).

They were also associated with greater levels of perceived self-efficacy and a stronger internal locus of control around ability to manage behavioural difficulties. Reflecting on achievements in successfully implementing such strategies to manage behaviours was also associated with a sense of pride and a positive perception of one’s ability to negotiate future challenges.

“I already have [made changes]. I don’t blow up no more. I don’t hit out. I don’t hit the staff. I don’t hit me friends. I just hurt meself. And that’s all. And that’s something I’m learning, I’m learning a little bit how not to do it” (Alice).

Participants who employed predominantly external understandings of their behaviour also described using some internal self-management strategies, such as writing things down or reminding themselves of their goals. However, the ability to employ these strategies was constrained within a narrative in which staff were viewed as powerful dispensers of justice; participants were able to use self-management strategies to avoid becoming drawn into aggression, but in a context in which they expected staff to deal with the perceived wrong-doer:

“I just wrote them down. And take it to the group (staff) so I can explain to them, and then that person could get in to trouble” (David).

There was also increased reliance on escape or avoidance behaviours as a self-management strategy in the absence of an understanding of the internal processes underpinning incidents of challenging behaviour. For example, Roger, Brian and Jack reported needing to avoid or leave certain situations or people in order to manage their

behavioural difficulties. This in turn was associated with less perceived control over behaviour:

“Then I had to go to my bedroom to calm down. [If I didn’t] well I would have flipped out, wouldn’t I?” (Roger).

Several service level factors were linked with the development of a more internal understanding of behaviour. First of all, it appears that nurturing systemic contexts that are sensitive to changes in the individual’s behaviour and respond accordingly are necessary in order to facilitate this level of insight. Alice noted an improvement in her ability to understand her behaviour when she was in a context in which the staff and her peers were kind. Secondly, several participants who considered their behaviour in more internal terms cited their experience in insight-oriented therapeutic groups as a key facilitator of this understanding:

“It (therapy group) helped me realise. [...] What I’m doing and what’s keeping me angry and that, and the stuff I can do” (Andrew).

Finally, reflective conversations with a supportive staff member following an incident, in which thoughts, feelings and alternative courses of action throughout the incident were discussed also appeared to be key in the development of insight.

“We started talking about it and going over it (what happened) [...] it helped me” (Sarah).

1.2 Sub-theme 2: External understandings of challenging behaviour

The analysis suggested two ways in which participants could understand their behaviour at an external level. Firstly, behaviours could be understood as a direct linear response to external events over which the individual had little control or responsibility.

Secondly, they could be construed as occurring within hostile cycles of interaction. These cycles were perceived to determine the parameters of the challenging behaviour (i.e. challenging behaviour is rarely thought to occur outside of these cycles), however the individual retained some responsibility for their role within these interactions. Hostility from peers was the most common external event believed to create challenging behaviour in both of these understandings, although staff behaviour was also a notable trigger in one account. David, Jack and Roger perceived their behaviour as a direct linear response to the behaviour of their peers:

“People get in my face, I start flipping” (Roger).

Similarly, Brian viewed his behaviour as a direct linear response to the presence of a particular staff member:

“I’ve been known to struggle with one of the staff members.[...] I couldn’t bear him hanging around me[...] Sometimes he can get to me, like when I see him hanging around or anything like that” (Brian).

Although Sarah understood her behaviour as occurring within the parameters of hostile interactions with her peers, she understood it more in terms of a circular causal chain in which her own actions also played a role in maintaining these hostile interactions.

“There was a girl I know and I used to have fights with her all the time. She would fight with me and I would fight with her. She’d argue over her clothes and I’d argue over mine” (Sarah).

Participants who employed this explanatory model relied heavily on environmental change and staff intervention as a means of reducing challenging behaviour. Environmental change was seen as key in bringing about long-term reductions in challenging behaviour, and

staff intervention was viewed as key in preventing specific situations from escalating into challenging behaviour:

“Well the way I feel now is completely different, living a new life, everyone that lives here and they’re alright. There’s no idiots, so it’s alright” (Jack).

Although these strategies were associated with reductions in challenging behaviour, these benefits were constrained to the context of this particular service. Furthermore, reliance on staff intervention could create a degree of passivity and a need for continued environmental management in order to maintain gains:

“There’s not much I can do about it (behaviour)” (Brian).

However, David and Sarah evidenced the use of more active strategies to attempt to change the environmental triggers to their difficulties. David described approaching his advocate and solicitor in order to effect meaningful change to his environment:

“Plus I can talk to, like, the ward manager, at my old place. Plus, me advocate and me solicitor. Then, next time around, they make sure that I get there [family visits] on time” (David).

Sarah also noted some proactive strategies she intended to undertake in order to better manage hostile interactions with her peers. Specifically, she expressed a desire to develop more positive relationships with her peers, so that she could “*get used to them*” and resolve conflicts with them more effectively.

Thus, viewing challenging behaviour primarily as a response to external events could promote both passive and active change strategies. Passive strategies, such as reliance on staff to produce environmental change, had benefits in terms of removal of the contingencies which maintained challenging behaviour but could promote passivity and result in future

goals being constrained by challenging behaviour, as participants expressed requiring continued staff presence and/or a continued means of separating themselves from peers in order to continue to manage behaviour. Active change strategies, however, could produce significant environmental change and promote positive beliefs in terms of hope to achieve future change, as participants employing these strategies expressed a stronger belief in the likelihood of experiencing behavioural improvement.

Participants who understood their behaviour more in terms of a response to environmental events described past exposure to quite extreme environments in which they had very little agency. With the exception of Sarah, who also possessed quite a strong understanding of the internal events underpinning her behaviour, these participants were also less likely to reference experiencing insight-oriented approaches or reflective conversations with staff members.

2. Master Theme 2: Positive relationships act as a buffer to challenging behaviour

As described above, negative relationships could lead to challenging behaviour by creating triggering situations. However, positive relationships were viewed to have a more long-term beneficial relationship with challenging behaviour. Several qualitatively different kinds of positive relationship were referred to, with each acting in a slightly different way to buffer against challenging behaviour.

2.1 Sub-theme 1: Positive peer relationships.

Most participants indicated the importance of positive peer relationships to their well-being. Key features of positive peer relationships that were evident across accounts included the presence of reciprocal kind acts, a shared sense of humour, and engaging in or conversing about shared interests. Positive peer relationships appeared to operate through a number of

mechanisms to act as a buffer against challenging behaviour. For some participants (David, Jack, Roger, Brian) improved relationships with their peers simply reduced the likelihood of the hostile interactions which triggered their behavioural difficulties. However, several additional buffering mechanisms were in operation for other participants. Firstly, positive peer relationships facilitated feeling safe and liked in the minds of other people, which in turn generated feelings of contentment, calmness and security:

“They always like us[...]It makes us happy” (Alice).

Secondly, they functioned as a key driver fuelling motivation to learn strategies which would allow participants to limit the impact of behavioural difficulties on friendships:

“Um, I’ll think things through cause of (housemate)” (Heather).

Finally, positive peer relationships also served to provide a safe context in which conflict resolution and relationship repair skills could be learned;

“We do fall out, but we always make it up again. [...] Either one guy apologises, or the other guy does” (Alice).

2.2 Sub-theme 2: Positive staff relationships.

Positive staff relationships were described in qualitatively different terms than positive peer relationships and were seen as operating through different mechanisms to deter challenging behaviour. Specifically, positive staff relationships were characterized by a sense of trust within which the staff member could be approached to confide in or to provide advice, guidance and support with problem solving. Thus, they functioned to provide a direct regulatory effect on the distressing emotions underpinning challenging behaviour for some of the participants.

“If I’ve got any problems they can sit me down to talk to me about what’s happened. And if they couldn’t sort it, that they’d probably take it to higher up, to the person who’s in charge, the nurse in charge” (David).

“The staff are kind here.[...]. They talk to me (when I’m upset). We go up to my bedroom and we talk” (Alice).

Positive staff relationships also helped participants to feel understood and to feel that their well-being was held in high regard by others:

“They want to see you happy” (Sarah).

Several facilitators of positive staff relationships were identified, most notably staff time, staff competence, and staff attitude:

“If someone’s calm with me, I’m calm with them. If someone comes in with attitude... You know what I mean?” (Andrew).

2.3 Sub-theme 3: Positive family relationships.

Where they were present, positive family relationships were felt to be very valuable to participants, and again appeared to function slightly differently to other positive relationships in how they related to challenging behaviour. Firstly, positive family relationships provided participants with a sense of belonging and provided opportunities to fulfil valued relationship roles outside of the service context (such as brother, uncle, sister).

I went to my Dad’s 80th birthday last year. It was really lovely to have all of my family there. All my cousins and nephews and aunts. It means a lot to me. I got a photograph in my room of me, my sisters, and my Dad together. I always want it like that (David).

Indeed, Sarah differentiated between the relationships she had with her family, which she valued above all other relationships, and the other main relationships in her life which took place in a service context and were characterized by “caring/look after” dynamics:

“I think the most important thing to me is my family. And then people that look after me in training, people that look after me up to a point, the nurses, the doctors and medical people, managers” (Sarah).

These benefits in turn drove the development of long-term goals around spending more meaningful time with family, which drove motivation to manage challenging behaviour in order to achieve these goals:

“My goals are to move to a community house in (place name deleted). Cause I’d be closer to family.” (Brian).

3. Master Theme 3: A greater ability to exert power and control in day to day life was perceived to promote long-term reductions in challenging behaviour

The degree of power and control that participants held over their environments was also a widely expressed theme across accounts. There were two separate feedback loops through which power and control were seen to be related to challenging behaviour. The first relates to the relationship between holding power and feeling trusted by the service. The second relates to the relationship between holding power and being able to make meaningful choices which make a difference to day-to-day life. Each of these feedback loops is discussed in more detail in the sub-themes below. The final sub-theme discusses participant experiences of some strategies which have successfully bridged the gap between empowerment and risk.

3.1 Sub-theme 1: Power and trust.

Being afforded additional liberties and control over their environments indicated to clients that they were trusted by the service, and that those around them had noticed the

progress that they had made. This in turn motivated the individual to attempt additional progress in the management of challenging behaviour, which resulted in continued independence, thus forming a virtuous cycle of progress. *Well I go out and watch the football, with the staff. And I tell them I'm going to the toilet, and they let me go to the toilet by myself. And I come back to my seat. So now...everything's looking up for me (David).*

Conversely, continued restrictions, particularly when this contrasts with perceived progress, promoted feelings of frustration and a perceived lack of control when changes in behaviour did not result in a corresponding change in level of restriction, which in turn maintained or increased the frequency of challenging behaviour, resulting in a vicious cycle:

"They said 12 months in [service] but instead they kept me in there for 2 years and 6 month. Longer than what I should've been there for. [...] It's annoying."
(Jack).

Thus, failing to recognize even small progress and retaining restrictive practices for long periods of time resulted in feelings of frustration and a deteriorating relationship with the service.

3.2 Sub-theme 2: Power and choice.

Being given greater levels of power and control over their own environments also enabled participants to exercise more choice and to engage more in meaningful activities. This enabled them to both build a more meaningful life for themselves and to develop a more positive relationship with the service. Both of these factors promoted a greater sense of well-being, which created a higher threshold required for triggers to result in challenging behaviour and greater motivation to manage behaviour. This in turn resulted in further decreases in challenging behaviour, which resulted in even further gains in power and choice. Thus, a positive feedback loop is formed. *You have more freedom here. I know you can't go*

out on your own, but staff take you out. You can go out, if it's a nice day you can walk in to town. Or take a bus back home, or walk back. I just finished a course, so I did (Alice).

When there was an absence of choice and opportunity, overall service relationships deteriorated, and participants reported increased levels of boredom, frustration and anger. This in turn increased the likelihood of situational triggers resulting in challenging behaviour, with increased frequency of challenging behaviour resulting in further restrictions on choice and opportunity. Thus, a negative feedback loop was formed: *It (past placement) was all closed in. I used to get bored there. I used to be cranky, I used to be bored, I used to be cross. They put me in security and everything. I didn't like it. Because I just wasn't happy.[...]. people were getting out and I wasn't (Sarah).*

3.3 Sub-theme 3: Bridging the gap between empowerment and risk management.

Some accounts tentatively pointed to the value of a collaborative risk management process as a means through which increased empowerment could be facilitated whilst still paying due regard to risk management. Both David and Sarah referred to a graded support plan which enabled them to collaboratively assess risks with a staff member and ensure that contingency plans were in place to address them. The use of such an approach was associated with both effective risk management and an increased sense of power and control. *I write things on it before I go out.[...]Like, first of all (we write) where the trip is going to be.[...]And I got meself a code word. Then we'll put down (risk situations). And if I can't get out of the situation, I can tell the staff and we can go another way. And the last time I done that, it worked out perfectly for me (David).*

Figure 1: Diagrammatic representation of themes identified and their relationships

[INSERT FIGURE 1 HERE]

Discussion

This study is consistent with the existing qualitative literature in this area, and offers further detail. Previous literature has demonstrated that people with intellectual disabilities use external and internal models to explain their behaviour (although one individual may, of course, employ different models at different times). For example, participants in previous research have constructed challenging behaviour as a response to negative relationships (Duperouzel & Fish, 2010; Fish & Culshaw, 2005) or as a response to internal mental distress (Brown and Beail, 2009). Findings around feelings of loss, sadness or anxiety precipitating aggressive behaviour are also consistent with recent research demonstrating that referrals for aggression often mask an underlying depression in people with learning disabilities (Jahoda, Melville, Pert et al., 2015; Willner, Rose, Jahoda et al, 2013). Previous research has also identified the potential benefits of service users holding perceptions of greater personal control over their challenging behaviour (Hawkins et al., 2005; Ruef & Turnbull, 2002). However, previous research has not offered an explanation for how people with intellectual disabilities come to hold such different understandings of their behaviour, and what the broader consequences of these understandings might be. This research allows us to make some small steps in conceptualising how such understandings might develop, although of course the small sample size precludes any definitive conclusions.

Our findings suggest the importance of service-level practices, such as a nurturing environment, structured reflection on incidents and the provision of insight-orientated interventions in shaping these understandings . Similarly, our analysis highlights that internal understandings promoted greater perceptions of control but could generate self-blame, whereas contextual understandings could highlight potentially harmful negative

environmental contingencies but could also (particularly linear understandings) promote passivity, at least in this sample. Active change strategies, such as utilising advocacy services to achieve systemic change, or using self-directed coping strategies to manage difficult emotions, for each explanatory style were highlighted as important in countering negative effects. Employing skills training as a means of helping service-users change negative environmental contingencies may also be helpful.

These findings are consistent with early psychological theories concerning beliefs about causality and one's ability to effect change (Bandura, 1994, 1997; Rotter, 1954; in Stainton-Rogers, 2011), in which an internal locus of control is associated with higher self-efficacy but can drive self-blame for perceived failures, with an external locus of control having the opposite effect (e.g. Halloran, Dumas, John & Margolin, 1999). However, the impact of disability, both socially and cognitively, on these processes also should also be acknowledged. Socially, an internal locus of control in the absence of an understanding of contextual factors may be an inappropriate goal in populations typically subject to negative social discourses and abuses of power. Cognitively, the ability for abstract thought underpinning insight will be limited by an individuals' level of intellectual disability . However, interventions are currently being developed to assist people with intellectual disabilities to develop the skills required to participate in insight-oriented interventions (e.g. Vereenoghe, Gega, Reynolds & Langden, 2016). Individuals with lower levels of intellectual ability may also need scaffolding from those around them to access some of the active change strategies identified in the study – the Active Support framework, in which staff sensitively manage the individual's environment in a way which maximizes opportunities for skill building, may be a useful framework for achieving this (Mansell & Beadle-Brown, 2004).

The buffering impact of positive relationships on challenging behaviour is also consistent with previous research in this area (Ruef & Turnbull, 2002; Reuf et al., 1999), although staff relationships in this analysis were perceived more positively than in previous research (Brown and Beail, 2009; Duperouzel & Fish, 2010; Fish & Culshaw, 2005; Griffiths et al., 2013). Our analysis points to some of the features of positive staff relationships, in addition to adding to previous research by elucidating the mechanisms through which positive relationships operate to moderate challenging behaviour.

Specifically, positive peer relationships provided a context in which people with intellectual disabilities could develop adequate conflict resolution and relationship repair skills, helped the participant to feel liked by others, and drove motivation to learn to self-manage behaviours to prevent them from impacting on relationships. Positive staff relationships supported regulation of emotion and served as a source of guidance and advice. This finding lends further support to recommendations on the provision of Active Support (Mansell & Beadle-Brown, 2004), in which staff utilise their positive relationship with the service-user to promote the development of new skills. Positive family relationships provided a sense of belonging and the opportunity to participate in valued social/relationship roles which were not characterized by a “looked after” dynamic. The value of a reciprocal relationship with a carer and the distress when experiencing a shift in this dynamic, is often expressed by people who have experienced an acquired disability (e.g. Jones & Morris, 2013; Kao & Stuijbergen, 2004). Overall findings on the benefits of positive relationships in reducing challenging behaviour highlight the importance of participation in valued and supportive relationships in improving quality of life, a core underpinning value of the PBS model (Hastings et al., 2013; Gore et al., 2013).

As in previous studies (Fish & Culshaw, 2005; Harker-Longton and Fish, 2002; Hawkins, Allen & Jenkins, 2005; Jones & Kroese, 2006; Sequeira and Halstead, 2001),

perceptions of powerlessness in this study were linked to feelings of frustration and anger. However, our analysis also suggests some direct links between perceptions of power and challenging behaviour, and offers some insight into the processes through which these concepts relate to each other. Two separate processes were identified, which could be either positively or negatively valenced. Firstly, when settings offered increased power and independence this communicated trust to the client and was taken as a sign their progress had been recognized, with this positive reinforcement driving further progress. Conversely, little change in levels of power and independence promoted frustration and prevented progress in reducing challenging behaviour. Secondly, increased power to exert greater choice in day-to-day living enabled more engagement with meaningful activity, with this in turn increasing well-being and thus enabling participants to cope better with potential triggers for challenging behaviour. Conversely, a restricted ability to exert choice and engage with meaningful activity promoted boredom and frustration, decreasing this coping ability. These processes are consistent with theories highlighting the role of disempowering environments in promoting “learned helplessness” (DeVellis, 1977; Foy & Mitchell, 1990; Kahana, Kahana & Riley; in Fry, 1989; Seligman, 1974;) and the role of meaningful activity in building positive mood (Lewhinson, 1994; Jahoda et al., 2015; Jahoda, Melville, Cooper et al., 2015). There is of course a need to balance increasing power and control with adequate risk management and meeting an individual’s support needs – a collaborative risk management process was identified in this study as a means of bridging this gap. Such findings are also supportive of PBS principles of stakeholder participation, inclusivity, and a move away from restrictive practice (Gore et al., 2013).

These findings, together with previous research, enable us to make some tentative practice recommendations for practitioners in services working with individuals with intellectual disabilities and challenging behaviour. These recommendations can be considered

at multiple levels within which psychologically informed principles can be used to maximize service-user benefits.

The findings suggest several actions at an organizational level. In relation to power and control, structures and mechanisms which enable collaborative approach to risk management would enable the positive feedback loops described earlier to be enacted. Goal planning can provide a mechanism through which progress could be reviewed and acted upon on a regular basis, and has been demonstrated to be effective in improving behaviour regulation in other rehabilitation settings (e.g. Wade, 2009). Service-users' desires for supportive personal risk taking and a more collaborative approach to risk management have been documented in other studies (e.g. Clark et al., 2005). Where possible, facilitating service-user input into their own functional assessment and formulation would also enable the development of this more collaborative and trusting relationship.

The frequency with which hostile peer interactions were considered as triggering challenging behaviour highlights the need for increased attention to placement planning. The importance of family relationships to well-being and challenging behaviour management also speaks to organizational practices. Facilitating appropriate family relationships should be a priority for the service. Furthermore, if it is not possible to facilitate such relationships within the family, efforts should be made to facilitate participation in other social relationships not characterized as "looked after/carer"; this could be facilitated through opportunities for social/community participation outside of the service. Indeed, increasing emphasis on dating and friendship agencies in intellectual disability services have been called for by service-users (Mason, Timms, Hayburn & Watters, 2013).

The findings can also inform staff training. Given that peer relationships conferred benefits at least partially through providing a context for conflict resolution skills, these

benefits could be harnessed by training staff to use peer disagreements as a naturalistic means of developing conflict resolution and relationship repair skills. Similarly, given that staff relationships confer benefits through the provision of emotional support, advice and guidance, staff training on maximizing these skills could be implemented. Some of the findings suggest potential for more direct psychological input at a group level, particularly as a vehicle for developing active change strategies. Change strategies experienced as useful in this analysis included analysing thoughts and feelings, engaging in structured problem-solving, drawing on a range of self-soothing strategies, engaging with advocacy services, and developing skills in conflict resolution. Group formats have demonstrated efficacy as vehicles for delivering these interventions (e.g. Hellenbach, Brown, Karatzias, & Robinson, 2015; Preston, 1998; Wilner et al., 2013), and can provide added benefits in terms of normalization and peer bonding opportunities (MacMahon et al., 2015).

Finally, the findings regarding different explanatory styles for challenging behaviour, each with its own strengths and weaknesses, highlight the need for service-users to have the opportunity to access individual psychological input which would enable them to develop a multi-layered understanding of their own behaviour. This would safeguard against potentially harmful processes associated with over-reliance on one style (e.g. self-blame, learned helplessness) and would enable change strategies to be implemented with greater effectiveness. There is a body of literature demonstrating that psychotherapeutic models such as CAT, narrative therapy and CBT can be successfully applied with individuals with intellectual disabilities (Foster & Barnes, 2009; Hartley et al., 2015; Oathamshaw & Haddock, 2006; Kellett, Beail, Bush, Dyson & Wilbram, 2009; Vereenooghe & Langdon, 2013). Change strategies derived from these understandings could then be implemented either in continued individual therapy or in some of the group skills training models described above.

However, these recommendations are constrained by a number of methodological limitations, in particular sampling issues. As a consequence of the necessity to be verbally able to be interviewed, the individuals who took part in this study all functioned at a relatively high intellectual level, and most likely presented with a high-moderate to mild level of intellectual disability. Thus, the findings cannot be assumed to be transferable to individuals with severe to profound intellectual disabilities. Participants varied considerably in the type of behaviour they presented with, their past experiences with services, and the interventions they received. All of these factors are likely to influence how service-users understand their behaviour. Although some variation is helpful in maximising the transferability of findings, too much may mask variability in how understandings are constructed (for example, it is possible that individuals who solely engage in self-harm employ different processes for understanding their behaviour than individuals who present with aggressive behaviour to others.) As with all IPA research, our study rests on the assumption that participants' verbal descriptions reflect underlying stable concepts, as opposed to being constructed through the process of the interview. However, we recognise that the stability of findings may be less certain in an intellectual disability population where acquiescence can be an issue in interviews (e.g. Rapley & Antaki, 1996). Repetition of this study would therefore lend further weight to our conclusions that such understandings' and explanatory styles are relatively stable over time.

A programme of research involving multiple studies of this phenomenon but employing tighter sampling criteria would enable the parameters of different levels of understanding to be better defined. Quantitative research could further add to the research base in terms of testing out some of the hypotheses and recommendations generated by this analysis and past qualitative research, such as whether accessing a friendship or dating agency results in greater relationship role satisfaction and well-being. Furthermore,

examining the degree to which service-users are currently facilitated in providing input into their own functional assessments, as well as the congruity between their own understanding of their behaviour and the formulation derived by the functional assessment, would represent a pertinent area for future research. Discrepancies between service-user understandings and the findings of a functional assessment could occur for a range of reasons (for example, service users may not provide accurate information on their behaviour), however this could highlight the development of a shared understanding as an important area for intervention.

To conclude, service-users possess a rich understanding of their own challenging behaviour and how it relates to processes around them. This understanding can be harnessed in order to improve service delivery at multiple levels. Additional research, both quantitative and qualitative, will create further grounds for implementing these changes.

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