THE UNIVERSITY OF HULL

Exploring the Implementation of Positive Behaviour Support as an Intervention for People with Intellectual Disabilities and Behaviours that Challenge.

being a thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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Overview

This portfolio thesis is comprised of three parts. It explores the implementation of positive behaviour support (PBS) to support people with intellectual disabilities and behaviours that challenge.

Part one contains the systematic literature review that aimed to explore the effects of implementing PBS in services that support people with intellectual disabilities and behaviours that challenge. Fourteen papers were analysed using narrative synthesis and five themes were constructed, including: 'reduction of behaviours that challenge', 'reduction of the use of psychotropic medication', 'improvements in quality of life', 'changes in the extent of support required' and 'elements of positive behaviour support which assisted changed in outcomes post-implementation'. The quality of the literature included is assessed, and the implications for clinical practice and future research are discussed.

Part two contains the empirical paper that aimed to explore the experiences of health care assistants who used PBS in an inpatient service to support people with intellectual disabilities and behaviours that challenge. Six participants shared their experiences in semi-structured interviews. The transcripts were analysed using interpretative phenomenological analysis and three superordinate themes were constructed: 'understanding behaviours that challenge', 'using PBS as a HCA' and 'relationships'. The clinical implications and future research suggestions are discussed.

Part three contains the appendices that accompany both the systematic literature review and the empirical paper. A reflective statement on the researcher's experiences of the research and an epistemological statement on the researcher's assumptions are included.

Table of Contents

List of Tables and Figures

Systematic Literature Review

Empirical Paper

Part One: Systematic Literature Review

This paper is written in the format ready for submission to the Journal of Applied Research in Intellectual Disabilities.

Please see Appendix C for submission guidelines.

What are the Outcomes of Implementing Positive Behaviour Support as an Intervention to Support Adults with Intellectual Disabilities and Behaviours that Challenge? A Systematic Literature Review

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Abstract

Background: Positive Behaviour Support has been implemented in services to support adults with intellectual disabilities and behaviours that challenge. The framework suggests it improves the quality of life and reduces behaviours; however, the outcomes have not been systematically reviewed.

Method: A systematic search of the literature was conducted and a narrative synthesis was utilised.

Results: 14 papers were identified and quality assessed. Five themes and seven subthemes were generated related to the outcomes of implementing PBS.

Conclusions: The quality of the papers was mixed and had limitations. Themes covered the positive outcomes of PBS and the components that contribute to them including improvements to the quality of life, improved quality of relationships, reduction in medication use and reduction of behaviours that challenge. Implications for the use of PBS are discussed.

Keywords: Positive Behaviour Support, Behaviour that Challenges, Intervention, Narrative Synthesis, Experiences, Outcomes.

Introduction

Behaviours that challenge describe “behaviour of such an intensity, frequency, or duration as to threaten the quality of life and/or physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion” (Banks, Bush & Baker, 2007, p.13). Behaviours that challenge are observed in many client populations, including around 10-15% of adults with intellectual disabilities, with the most common behaviours being self-injury, aggression, and destructive behaviour (Emerson et al., 2001). Vulnerability factors include health issues, genetic factors, communication difficulties, and poor engagement for people with intellectual disabilities and behaviours that challenge (Bowring, Totsika, Hastings, Toogood & Griffith, 2017).

Positive behaviour support (PBS) is a framework that has been created to support individuals whose behaviours may challenge. PBS is described as a "multi-component framework" that aims to understand the function of behaviour and the physical and social environment to enhance a person’s quality of life (Gore et al., 2013). The PBS process includes a functional assessment that is supported by observational data, from which interventions are developed to reduce the frequency of behaviours that challenge and increase quality of life (PBS Academy, 2015). PBS can be implemented on an individual level, with professional teams, and through system-wide approaches in settings such as residential homes, schools, and family homes (Gore et al., 2013). PBS plans include a range of strategies to guide care staff. The strategies are predominantly proactive to reduce the likelihood of behaviours that challenge occurring, including environmental changes, adapting interactions, and teaching the individual skills that provide functionally equivalent alternatives to behaviours that challenge (Gore et al., 2022). In addition, the plans include non-aversive reactive strategies to minimise harm and the use of restrictive practices where there are indicators that behaviour may occur or in the instance it does occur (Gore et al., 2022).

PBS is centred around Applied Behaviour Analysis (ABA; Baer, Wolf, & Risley, 1968), which influenced the functional behavioural assessment element of PBS. PBS formulates using the “four-term contingency” theory, assessing the behaviours and consequences, and establishing operations and discriminative stimulus to understand the behaviour that challenges (Toogood, 2012). The functional assessment and the understanding of the behaviours directly inform the intervention. The distinction between ABA and the PBS framework is in the application of the principles to complex settings and implementation at multiple levels (Dunlap, Carr, Horner, Zarcone & Schwartz, 2008). This includes direct contact with the individual and those supporting them, in a supervisory context for systems supporting the individual and embedding PBS into services (PBS Academy, 2015).

PBS is underpinned by principles of normalisation and inclusion, the philosophy that people with intellectual disabilities should be included in the same settings and have the same types of opportunities as others without intellectual disabilities (Carr et al., 2002). Furthermore, PBS should be person-centred, utilising person-centred planning where the person’s needs are considered within the intervention and using self-determination principles to empower the individual to make decisions, participate in goal setting and self-advocate (Carr et al., 2002). Therefore, PBS can be described as a “wraparound approach” where interventions are tailored to the individual's needs and the physical and social environment surrounding them (Clark & Hieneman, 1999).

There are several distinctive features of PBS, as defined by Carr et al. (2002), that are integrated to facilitate the overarching goal of improving quality of life and reducing behaviours that challenge. One way to assess the success of a PBS intervention would be to look at the changes to an individual's lifestyle and quality of life domains such as social relationships, employment, recreational activities, and community integration (Hughes, Hwang, Kim, Eisenman & Killian, 1995). The PBS intervention must take a lifespan perspective, meaning the change may take time to achieve and the maintenance of change is important. Therefore, the intervention must be evaluated and modified to support the person across their lifetime (Carr et al., 2002). Finally, stakeholder participation is central to the development and implementation of PBS. This includes the individual and their support system collaborating as they are the experts in their experience (Carr et al., 2002).

A review by Heyvaert, Maes and Onghena (2010) appraised the effectiveness of interventions used to support people with behaviours that challenge. This was a meta-analysis of a broad range of interventions including biological, psychotherapeutic and contextual; however, it was unclear if PBS was included in those interventions. There was an overall positive treatment effect for behaviours, but there was little difference noted between the interventions. A review identified variables that contribute to the successful implementation of PBS within disability services; this included brain injury, autism and intellectual disability services (Hayward, Poed, McKay-Brown & McVilly, 2021). Twenty-six factors were identified, but the impact this had on the service users or the systems around them was not discussed. Other reviews on interventions, such as the role of sensory integration in supporting behaviours that challenge, have been conducted but this was not specifically linked with the use of PBS (McGill & Breen, 2020). Furthermore, the outcomes focused on reducing behaviours that challenge and restrictive interventions.

Literature reviews exploring the outcomes of PBS have focused on changes after PBS training for care staff. MacDonald and McGill (2013) explored the outcomes for service users and staff after staff attended PBS training. Reductions in rates of behaviours that challenge after staff training were reported, but there was no evidence of improvements to the quality of life of the service users. Mahon, Walsh, Holloway and Lydon (2021) evaluated the training procedures used in PBS training of staff to determine their effectiveness. This highlighted the most effective elements of PBS training and linked these to client outcomes, including reducing the rates of behaviours that challenge and improvements to quality of life. However, this review focused mostly on staff and service outcomes rather than those of service users.

The PBS framework aims to improve the quality of life of the person it is supporting and the lives of those around them and as a result of this, there is also a reduction in the behaviours that challenge. Previous reviews focused on evaluating the effectiveness of implementing PBS and the factors associated with its successful implementation. There has been less focus on the outcomes of implementing PBS for people with behaviours that challenge and the stakeholders in their care. When outcomes have been investigated, there is a weighted focus on behaviours that challenge and less so on the quality of life or other possible outcomes. Furthermore, the outcomes were centred on PBS training for staff rather than looking into the implementation of PBS over time with an individual or support services. The reviews mostly utilised quantitative data which excludes rich data on lived experiences of PBS. Furthermore, the voices of people with behaviours that challenge, their families and carers have not been heard.

Aims

This literature review aimed to understand the effects of implementing PBS within settings and services that support people with behaviours that challenge. The review gathered research articles that investigated the outcomes of PBS with adults with intellectual disabilities and discussed the implications this has for the individual, their families and carers, the support staff, and services.

Research Questions:

- What are the outcomes of implementing positive behaviour support for behaviours that challenge with adults with an intellectual disability?
- What are the effects of PBS on the individual, on the staff and family who support them and on the systems that implement the intervention?

Method

Search Strategy

The search aimed to find articles where PBS had been implemented as the main intervention to support people with behaviours that challenge- in a varying degree of contexts, from implementation in a residential staff team to specialist intensive support teams. An electronic database search of the literature was conducted between December 2021 and February 2022 using the EBSCO search engine. The research databases searched included Academic Search Premier, CINAHL Complete, MEDLINE, APA PsycArticles, and APA PsycInfo. The default search was used to ensure the highest probability of accessing the full range of the literature. The search terms used were:

"learning disabilit*" or "intellectual disabilit*" or "mental disabilit*" or "mental* retard*" or "learning difficult*" or "special need*"

AND

(challeng* or problem* or difficult* or issue*) N4 behav*

AND

"positive behav* support*" or PBS or "positive behav* intervention*"

A wide range of terms was included for intellectual disability to encompass the various labels that individuals may receive in the literature. Asterisk truncations were used to encompass spelling variations. Quotation marks allowed specific phrases and terms of interest to be searched for. The Boolean operator ‘AND’ was used to ascertain a wide range of articles while still being related to the search terms.

Selection Strategy

Once the initial search was run, duplicate and non-English articles were removed, and the results were refined to include only academic journals. The retrieved article’s title and abstract were screened against the inclusion and exclusion criteria (Table 1 and Table 2). If the articles were deemed suitable, they were then reviewed in full for suitability against the criteria. Figure 1 illustrates the screening process and the articles excluded.

Table 1. Inclusion criteria and rationale

Inclusion Criteria	**Rationale**
PBS as part of the intervention	The review is focussed on the outcomes of using PBS as the primary intervention
The intervention is used to support adults (18+) with intellectual disabilities and behaviours that challenge	The review is focussed on the use of PBS with adults with intellectual disabilities and behaviours that challenge
People with intellectual disabilities may have additional diagnoses (e.g. autism)	There are high comorbidities in the intellectual disability population
Service and family implementations of PBS	A broad exploration of implementing PBS
Qualitative, qualitative, mixed methods, and single case studies	A breadth of studies

Table 2. Exclusion criteria and rationale

Exclusion Criteria	**Rationale**
Books, systematic literature reviews, audits, surveys, response articles and commentary papers	Not Primary data
Participants are under 18 only	Not the population of interest
People without intellectual disabilities or behaviours that challenge	Not the population of interest
Schools implementing PBS	Not the service of interest
Outcomes of staff training	Exploring the implementation of PBS not the outcomes of staff training

Data Extraction

Salient information was extracted from each article individually using a data extraction form (see Appendix F). The data extraction form included information on the research aims, design and methodology, participant information, outcome measures (if used), results, and key findings.

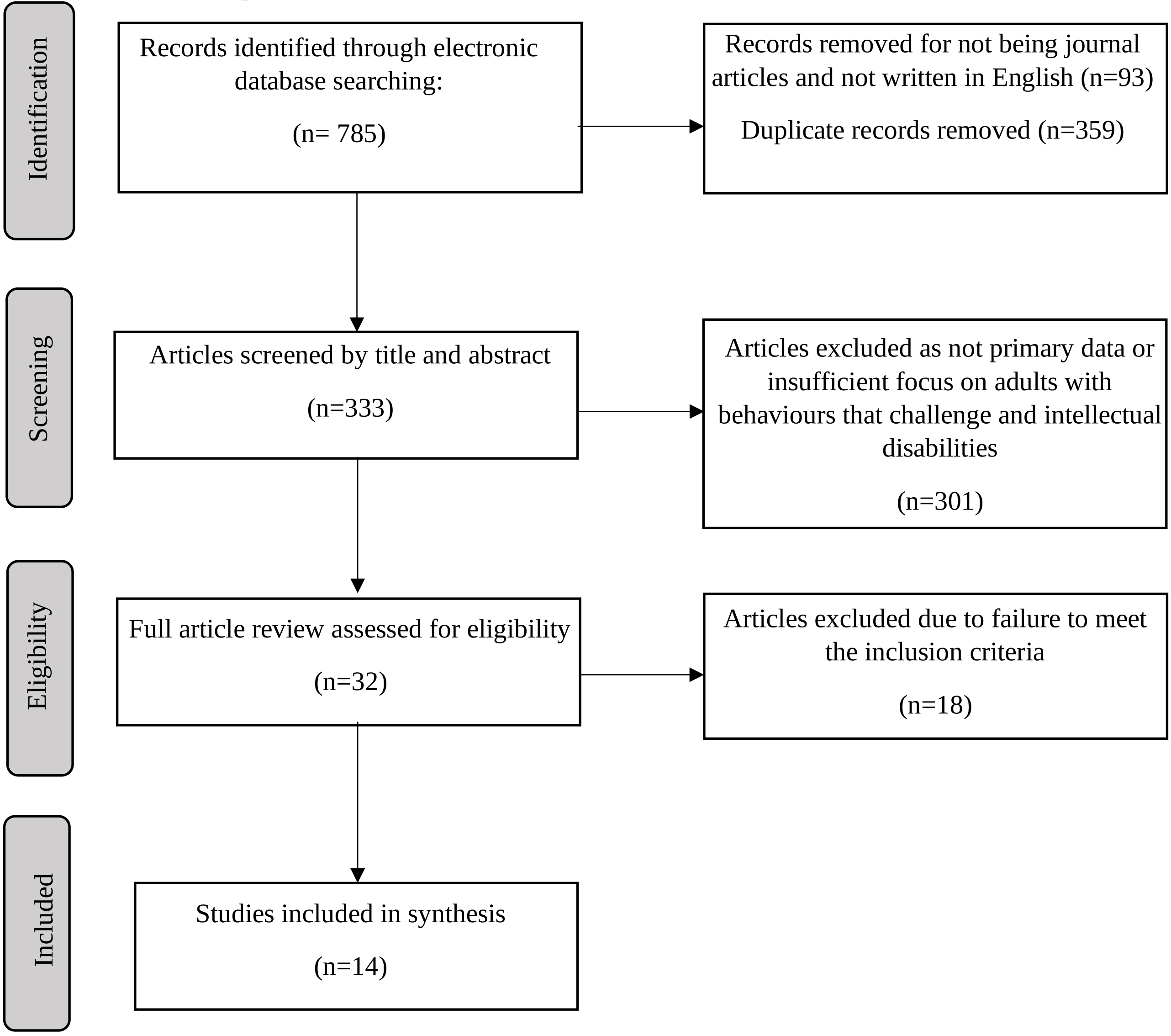
Quality assessment

The Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018) assessed the methodological quality of the studies (see Appendix D). This appraisal tool was selected as it can be used with studies of different methodologies. Using the MMAT algorithm for selecting study categories (see Appendix E), the studies were categorised into qualitative, quantitative randomised control trials, quantitative non-randomised control trials, and quantitative descriptive studies. All fourteen studies were rated against the two screening questions and then the questions for their appropriate categories. Question 4.4 was adapted according to guidance in the methodology quality criteria to better match case series and case reports. The studies were rated "yes", "no" and "can't tell" (CT). The ratings for the studies can be seen in Table 3. The mixed-methods category was not included in the table as none of the studies was categorised as such. To check the reliability of the rating, three of the studies were rated by a peer who was blind to the first rating. The ratings were compared, showing a 90.84% agreement. The minor disagreements were discussed until they were 100% agreed upon.

Data Synthesis

The papers included in the review used a variety of study designs to explore the topic of PBS interventions, and therefore it was not a homogeneous sample. A narrative synthesis (Popay et al., 2006) was selected to synthesise the results of the study as it can be used to synthesise quantitative and qualitative results to create a narrative of the findings which illustrates the relationships between them. Firstly, a preliminary synthesis of the findings was developed, which involved summarising the findings of each study and organising the findings to illustrate patterns across the studies in terms of the effects of implementing PBS. Tabulation and summaries of the results were used to summarise the features of the study and the results. Groups and clusters were created from common and significant findings. As patterns began to be developed, the characteristics and findings of different studies were explored, such as the variability in study designs, study populations, and outcomes. Ideas webbing, a visual technique that utilises spider diagrams, was used to group similar findings and illustrate the relationships between them to develop the themes (Popay et al., 2006). The robustness of the synthesis was assessed using quality analysis tools to determine the methodological quality of the studies. This allowed the strength of the evidence to be reported and how generalisable the findings of the synthesis were.

*Figure 1***.** *Article selection process*



Adapted from the "PRISMA Flow Diagram" (Moher et al., 2009).

Table 3. Quality Assessment Summary Table. Adapted from the MMAT (Hong et al., 2018)

Category of study designs	Methodological quality criteria	Conway et al. (2019)	Gerrard et al. (2019)	Inchley-Mort et al. (2014)	Lewis et al. (2021)	McClean et al. (2007)	McClean & Grey (2012)	McGill et al. (2018)	McKim & Samuel (2021)	McKenzie et al. (2018a)	McKenzie et al. (2021)	McKenzie et al. (2018b)	Toogood et al. (2011)	Webber et al. (2017)	West & Patton (2010)
Screening questions (For all types)	S1. Are there clear research questions?	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	N
	S2. Do the collected data allow to address the research questions?	Y	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	CT
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions														
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?								CT	Y	Y	Y			
	1.2. Are the qualitative data collection methods adequate to address the research question?								N	Y	Y	Y			
	1.3. Are the findings adequately derived from the data?								N	Y	Y	Y			
	1.4. Is the interpretation of results sufficiently substantiated by data?								N	Y	Y	Y			
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?								N	Y	Y	Y			
2. Quantitative	2.1. Is randomization appropriately performed?							Y							

randomized controlled trials	2.2. Are the groups comparable at baseline?							Y							
	2.3. Are there complete outcome data?							N							
	2.4. Are outcome assessors blinded to the intervention provided?							N							
	2.5 Did the participants adhere to the assigned intervention?							Y							
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	Y	Y	Y	CT	Y	CT								
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Y	N	Y	Y	Y	Y								
	3.3. Are there complete outcome data?	N	Y	Y	CT	Y	Y								
	3.4. Are the confounders accounted for in the design and analysis?	N	N	Y	N	N	CT								
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	Y	Y	CT	Y	Y	Y								
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?												Y	N	Y
	4.2. Is the sample representative of the target population?												N	N	N
	4.3. Are the measurements appropriate?												N	Y	Y
	4.4. Is the data complete?												N	Y	Y
	4.5. Is the statistical analysis appropriate to answer the research question?												N	N	CT

Results

Overview of the Included Studies

Fourteen studies were included in the review and they were published between 2007 and 2021 (see Table 4 for an overview of the studies). The research was mostly conducted in the UK (10) and Ireland (2) and the rest in the USA (1) and Australia (1). Four studies used qualitative methodologies to explore the experiences of PBS from the perspective of people with intellectual disabilities, family and carers and support staff. Data was collected through semi-structured interviews with individuals or in focus groups. The main method of analysis used was thematic analysis (3) and one study did not specify what type of analysis they utilised.

Ten studies used quantitative methodological approaches to investigate the outcomes of implementing PBS; a randomised control trial that compared the implementation of PBS in services to control groups (1); non-randomised studies where the effectiveness of PBS was investigated (6); two of which compared the PBS intervention to a control group; and four interrupted time-series and before and after intervention studies. Three studies used quantitative descriptive methodologies, specifically case series and case reports. Data was collected using various outcome measures of mental health and behaviours that challenge, the cost of social care, quality of life, occupation and medication (see Table 4).

PBS was implemented across a range of services, including social and residential care, supported living, and in the community. The services that provided PBS varied from specialist PBS teams, a complex behaviour service, a PBS clinic, and an intensive community intervention service. Sample sizes varied from single case studies to a large-scale randomised control study with 81 participants. There were 239 participants across the fourteen studies;

one study did not disclose the total number of participants. The characteristics of people with intellectual disabilities included in the studies ranged from “mild” to “profound” intellectual disability, and some had additional diagnoses of Autism and Down’s Syndrome. Two studies excluded people with “acute mental health disorders” and “substance misuse”. Other studies did not state this as an exclusion criterion, and in some studies, it was reported that the participants took antipsychotic medication. The behaviours that challenge for which they received support included self-injury, damage to property, physical aggression and verbal aggression.

Methodological Quality

The quality assessment showed a variation in the quality of the studies. Twelve studies provided clear research questions and the data collection allowed for the questions to be addressed. Two studies were not clear in their research questions and this consequently affected their overall quality assessment score. In the quantitative studies, the quality was mixed. Most of the quantitative non-randomised studies included participants representative of the sample and used measures appropriate to the outcomes of the intervention. However, they did not adequately account for confounders and there were no statistical measures in place to control for them. Quantitative descriptive studies were scored lower in their quality as the studies utilised small sample sizes which were consequently not as representative of the target population. The measurements used were largely appropriate and collected for all participants but the statistical analysis was limited. Two of the three observational studies included information regarding who collected the data. The data was collected by support staff which may increase the risk of bias. In these studies, inter-rater reliability was checked between independent ratings on outcome measures and demonstrated high inter-rater reliability coefficients. Most of the qualitative studies were of good quality and the approach was necessary to look at the experiences of the participants through individual interviews and focus groups. Furthermore, the findings were derived from the data and interpreted appropriately and coherently. One study had low-quality scores as the data was presented as case descriptions with little information on how the data was collected and how the findings were derived.

Table 4. Summaries of the Studies Included in the Review

Author, date and country of origin	**Research aims**	**Design and method**	**Participants**	**Key findings**	**Quality rating (Frequency of Y, N & CT)**
Conway, Perera, Courtenay, Tsolakidis & Gopal (2019) (UK)	To assess and review two interventions to reduce behaviours that challenge clients with intellectual disabilities	• Quality improvement methodology • PBS Clinic • MOAS and CGI were taken in clinic sessions- no information on the timing of the measures • Antipsychotic use was measured- no information on how this was measured or the timing of this	• 8 adults with mild to profound intellectual disabilities and behaviours that challenge • No severe mental illness • Using antipsychotic medication	• Aggressive behaviour, as measured by the MOAS, had a slight reduction and then increased (not significant) • Severity of illness ratings, as measured by the CGI scale, increased then decreased • Antipsychotic medication could not be reduced.	Y=5 N=2 CT=0
Gerrard, Rhodes, Lee & Ling (2019) (UK)	To investigate if PBS can support medication reduction To access the success of medication reduction with and without PBS To explore whether PBS can influence the reluctance to reduce medication	• Two-group experimental design. • PBS team group and control group. • All participants met with a pharmacist for reviews.	• 54 adults with an intellectual disability and behaviours that challenge • 25 in the PBS group • 29 in the control • Stable behaviours, stable epilepsy, no mental	PBS group: • More medication reviews • More likely to agree to initiation of medication challenge • More patients continued with medication reductions • More progressing to full discontinuation of meds	Y=5 N=2 CT=0

		• Specialist PBS team	health diagnosis, took psychotropic medication	• Less likely to require a medication increase or restart	
Inchley-Mort, Rantell, Wahlich & Hassiotis (2014) (UK)	Compare the clinical outcomes and social care costs of a Complex Behaviour Service (CBS) over 12 months with cases receiving usual care	• Observational study • No information on who collected the data. • Complex behaviour service (CBS) fully integrated into the community learning disability service • Outcome measures (ABC, HoNOS-LD, CANDID-s and PASSAD) were administered to assess the service users at baseline, six and twelve months • Multilevel regression	• 46 adults with intellectual disabilities and behaviours that challenge • No acute mental illness or substance misuse. • 24 in the CBS group • 22 in the usual care group	CBS group: • Significant reductions in behaviours that challenge, as measured by the ABC: irritability, stereotypy and total scores at 6 months • Reductions were maintained for stereotypy at 12 months. • Decreased risk • Weekly social care costs increased • No difference in secondary outcomes (mental and social functioning as measured by the PASSAD, met and unmet needs as measured by the CANDID-s, mental health status as measured by HoNOS-LD)	Y=6 N=0 CT=1

Lewis, Reynolds, Vale, Keenan, Hartland, Haines & Davies (2021) (UK)	To evaluate the effectiveness of PBS interventions implemented within the Intensive Community Intervention Service (ICS)	• Observational study • Outcome measures (CBI, HoNOS-LD, GCPLA, QoLC, REIS-SF and MOHOST) were completed pre-ICS involvement and post-ICS involvement. No information on the time period between pre and post-ICS intervention. • PBS and workshop training of staff and carers	• Individuals with intellectual disabilities and behaviours that challenge referred to the ICS team between 2010 and 2018	• Behaviours that challenge, as measured by the CBI, significantly reduced in intensity, frequency and duration. • Significant reductions in mental health difficulties, as measured by the HoNOS-LD • Significant improvements in quality of life, as measured by the GCPLA and the QoLC (adapted from the LEFC) • Resources available to support the person in occupational engagement significantly improved, as measured by the REIS-SF • Occupational participation improved, as measured by the MOHOST	Y=4 N=1 CT=2
McClean, Grey & McCracken (2007) (Ireland)	To evaluate the effectiveness of PBS in the community for those with severe behaviours that challenge	• Observational study • Data was collected by “programme staff” who supported the adults with behaviours that challenge for the Mini-PAS-ADD. It was unclear	• 5 adults with severe behaviours that challenge and intellectual disabilities	• Reduction to near-zero rates of behaviours that challenge, measured during periodic service reviews • Reduction in medication usage • Reduction in mental health problems, as measured by the Mini PAS-ADD • Reduction in revenue costs • Quality of life improvements, as measured by the QoLQ	Y=6 N=1 CT=0

		who collected data on the QoLQ. • Outcome measures (Mini PAS-ADD and QoLQ) were completed at baseline and at 6 months, 12 months and 18 months after the commencement of the study • PBS in the community			
McClean & Grey (2012) (Ireland)	To evaluate the impact of PBS intervention on target behaviour, mental well-being and quality of life	• Observational study • Data was collected by support staff • Behaviour support team • PBS was implemented in five phases (low arousal, rapport building, predictability, functional	• 4 participants with severe behaviours that challenge, severe intellectual disability and an autism spectrum disorder • Two adults, two children	• Behaviours that challenge, as measured by the CCB, reduced in the low arousal phase and to near-zero levels in the rapport-building phase and were maintained long-term • Staff ratings of behaviours reduced • Positive effect on mental health status measured by the HoNOS-LD and quality of life measured by the QoLS	Y=5 N=0 CT=2

		equivalent skills training, differential reinforcement) • Outcome measures (CCB, HoNOS-LD, QoLS) were administered at baseline, during the PBS intervention phases and at follow-up (1 year, 2 years and 3 years post-intervention)			
McGill, Vanono, Clover, Smyth, Cooper, Hopkins, Barratt, Joyce, Henderson, Sekasi, Davis & Deveau (2018) (UK)	To develop and evaluate a setting-wide PBS approach in supported accommodation settings.	• A pragmatic, cluster randomised, controlled trial • Used PBS principles to improve the quality of the experimental group in activities and skill development, service management, physical	• Residential settings that supported adults with intellectual disabilities and behaviours that challenge • Experimental group: 11 residential settings • Control group: 13 residential settings	PBS experimental group: • Behaviours that challenge reduced, as measured by the ABC, significantly more than the control group • Active support increased, as measured by the ASM, significantly more than the control group • An increase in meaningful activities, as measured by the EMAC-R, was not significantly more than the control group and quality of life improved • Staff, family members and professionals evaluated the intervention positively	Y=5 N=2 CT=0

environment, relationships with family and others, service staff, communication and social interaction, health, and the wider organisation

- The ABC measure was administered prior to group allocation, 3-6 months after the end of the intervention and 12-18 months after that
- The ASM was administered at baseline and 3-6 months after the end of the intervention.
- Engagement in meaningful activities (as measured by the EMAC-R) was measured at baseline and post-intervention.

		There is no information on when the post-intervention measure was completed.			
McKim & Samuel (2021) (UK)	Case description of individuals referred to an NHS intensive support team	- Case descriptions and staff and family interviews - Intensive support team	- Three adults with intellectual disabilities and behaviours that challenge - Referred to the intensive support team - Living in supported living	- Increased staff confidence and competence - Improved rapport - Increase in social and community activities - Reduced rates of behaviours that challenge and reduction in the severity - Improved quality of life - Increased positive behaviours	Y=0 N=5 CT=2
McKenzie, Mayer, Whelan, McNall, Noone, & Chaplin (2018a) (UK)	To understand how family carers conceptualised PBS and how they had experienced this in relation to their family member	- Three interviews and one focus group. - Inductive thematic analysis.	- 8 participants - Had adult children with intellectual disabilities and behaviours that challenge - Or had the experience of support for a family member with an intellectual disability	4 themes: - The bedrock of support - The impact of care - It's been a battle - He's my son	Y=7 N=0 CT=0
McKenzie, Murray & Martin (2021) (UK)	What is the impact of COVID-19 restrictions on the provision of PBS in social care settings to people with intellectual disabilities?	- Semi-structured phone interviews. - Thematic analysis - PBS in social care settings	- 19 participants representing 19 organisations - Staff who had completed the PBS programme and supported people with	3 themes: - It's been adapted rather than impacted - Everything's the same but not quite the same - In practice it's simple. In theory, it sounds like we have changed the world	Y=7 N=0 CT=0

			intellectual disability and/or autism		
McKenzie, Whelan, Mayer, McNall, Noone, & Chaplin (2018b) (UK)	Exploring the experiences of people with intellectual disability of PBS.	• Individual interviews and focus groups. • Inductive thematic analysis	• Seven adults with an intellectual disability and currently displaying or previously displaying behaviours that challenge • Experienced PBS	4 themes: • Being treated as a human being • A full and normal life • Contrast with restrictive practices • The positive impact of PBS	Y=7 N=0 CT=0
Toogood, Boyd, Bell & Salisbury (2011) (UK)	Describe functional assessment and intervention and the follow-up 10 years later	• Quantitative case study • PBS from an intensive support service and crisis prevention and management service • Retrospective sampling of ABC charts from 2008-2009 (10 year follow-up) • Active support measure administered in 2008 (10 year follow-up)	• A 32-year-old man with severe intellectual disabilities and autism • Displayed behaviours that challenge since childhood	• A steady reduction in behaviours that challenge (aggression, self-injurious behaviour, damage, vocal), as measured by ABC charts • Episodic severity lessened first then the rates reduced • The reduction was maintained after 10 years	Y=3 N=4 CT=0
Webber, Major, Condello &	Description of PBS to eliminate the use of mechanical restraint	• Quantitative case study	• A 38-year-old man with intellectual disabilities, behaviours that	• The use of mechanical restraint in both services was reduced and reduced to zero after 4 months	Y=4 N=3 CT=0

Hancox (2017) (Austalia)		• PBS in residential accommodation and day services to support an individual (started in 2014) • The reported use of mechanical restraint between January and December 2014 • The SIB-R was administered in January 2015 and December 2015	challenge and health problems	• Behaviour that challenge ratings increased due to pain, as measured by the SIB-R	
West & Patton (2010) (USA)	The use of PBS and supported employment	• Quantitative case series • PBS and supported employment services • No information on the frequency of the completion of ABC charts	• 4 adults with intellectual disabilities and behaviours that challenge • Lived in a group home • Limited or no contact with family • Attended a community-based agency	• All were able to perform their jobs independently and correctly after at least 14 sessions • No behaviours that challenge occurred in community settings and during training, as measured by ABC charts	Y=3 N=2 CT=2

Outcome measures:

ABC: Aberrant Behaviour Checklist (Aman, Singh, Stewart & Field, 1985).

ASM: Active Support Measure (Mansell & Elliott, 1996)

CANDID-s: Camberwell Assessment of Needs- Developmental and Intellectual Disabilities-short version (Xenitidis et al., 2000)

CBI: Challenging Behaviour Interview (Oliver et al., 2003)

CCB: The Checklist of Challenging Behaviours (Harris, 1993)

CGI Scale: Clinical Global Impression Scale (Guy, 1976)

EMAC-R: Engagement in Meaningful Activity and Relationships (Mansell & Beadle-Brown, 2005)

GCPLA: The Guernsey Community Participation and Leisure Assessment (Baker, 2000)

HoNOS-L: Health of the Nation Outcome Survey-LD (Roy, Matthews, Clifford, Fowler & Martin, 2002)

Mini PAS-ADD: Mini Psychopathology for Assessment Schedule for Adults with Developmental Disabilities Checklist (Prosser et al., 1998)

MOAS: Modified Overt Aggression scale (Kay, Wolkenfeld & Murrill, 1988)

MOHOST: Model of Human Occupation Screening Tool (Parkinson, Forsyth & Kielhofner, 2006)

PASSAD: Psychopathology for Assessment Schedule for Adults with Developmental Disabilities Checklist (Moss et al., 1998)

QoLC adapted from the LEC: Quality of Life Checklist adapted from the Life Experiences Checklist (Ager, 1993)

QoLQ: Quality of Life Questionnaire (Schalock, Keith, Hoffman & Karan, 1989).

QoLS: Quality of Life Scale (Kincaid, Knoster, Harrower, Shannon & Bustamante, 2002).

REIS-SF: The Residential Environment Impact Survey- Short Form (Fisher & Kayhan, 2012)

SIB-R: Scales of Independent Behaviour- Revised (Bruininks, Woodcock, Weatherman & Hill, 1996).

Key Findings

Emergent themes represent the experiences of PBS and how this impacted people with behaviours that challenge, the support around the person, those who implemented PBS and the services they were implemented in (see Appendix G). There was some insight into what elements of PBS were effective at supporting people with behaviours that challenge.

1.Reduction of Behaviours that Challenge

Twelve of the papers included in the review reported findings related to behaviours that challenge. Most of these papers illustrated a significant reduction in the frequency and severity of the behaviours; for instance, McGill et al. (2018) used a randomised control methodology to compare residential settings where PBS was implemented and a control group. The behaviour that challenge scores for residents reduced significantly more in the PBS group compared to the control group. Inchley-Mort, Rantell, Wahlich and Hassiotis (2014), showed a significant reduction in irritability and stereotypy behaviours six months after implementing PBS.

The reduction in behaviours that challenge often occurred soon after PBS was implemented. McClean, Grey and McCracken (2007) reported significant reductions within the first one to two months of implementing PBS. For two participants, the behaviours were reduced immediately after the implementation. One study gave insight into the stages of PBS, which may lead to a decrease in behaviour frequency (McClean & Grey, 2012). The researchers implemented PBS in five phases, aggressive and self-injurious behaviours were reduced to 46.7% of baseline rates after the first low arousal phase, and the addition of rapport-building interventions yielded a further reduction to 27.7% of the baseline rates. After all five phases were implemented the behaviour that challenge rates were reduced to nearly zero and were maintained at this level over three years.

Only one study explored the outcome of risk after implementing PBS. An overall reduction in risk to the person with behaviours that challenge and risk to others was illustrated in a complex behaviour service from baseline to 12-month follow-up (Inchley-Mort et al., 2014). Three studies explored the long-term implications of PBS. Reductions in behaviours that challenge were maintained to follow-up after 12–18 months, which was significantly more than the control group at follow-up (McGill et al., 2018). Similarly, intervention gains were maintained for 152 weeks (McClean & Grey, 2021). The case reported by Toogood, Boyd, Bell and Salisbury (2011) was followed-up ten years after PBS was implemented and the results suggested behaviours that challenge were reduced, but different measures were used at implementation and follow-up, so the rates are not directly comparable.

Two studies reported an increase in behaviours that challenge. Behaviours of aggression did not reduce in the PBS clinic (Conway, Perera, Courtenay, Tsolakidis & Gopal, 2019) and self-harm and property damage increased after PBS implementation due to internal pain experienced by the participant (Webber, Major, Condello & Hancox 2010).

2.Reduction of the Use of Psychotropic Medication

Over-medicating and inappropriate medication are issues among people with intellectual disabilities, particularly those with behaviours that challenge (Sheehan et al., 2015) and the reduction of this is the focus of the NHS England's campaign 'Stopping over-medication of people with intellectual disability, autism or both' (NHS England, 2016; NICE, 2017). One study estimated that 89% of the participants displaying aggressive behaviours were using psychotropic medication (Deb, Unwin & Deb, 2015). Antipsychotics were the only type of medication that was “challenged” throughout the implementation of PBS, the most common being risperidone (Gerrard, Rhodes, Lee & Ling, 2019). “Medication challenge” referred to the pharmacist’s review of medication prescriptions and the initiation of the reduction of medication. Medication was an outcome measured by several of the included studies. Medication reduction was part of the PBS plan to support the person with behaviours that challenge (McClean et al., 2007; McKim & Samuel, 2021; Toogood et al., 2011). As part of the PBS approach, medication reviews were more frequent, which allowed the medication to be reduced safely and the side effects to be monitored. For example, Gerrard et al. (2019) used medication reviews to educate on medication, assess physical health and monitor side effects, and the results illustrated that more medication reviews were attended by people supported with PBS than the control group. Medication was reduced after the PBS plans were implemented (McClean et al., 2007; Gerrard et al., 2019) and was successfully discontinued for 60% of participants (Gerrard et al., 2019). In one study, the medication reduction was related to the reduction of behaviours, and because the behaviours did not reduce, the antipsychotic medication could not be reduced (Conway et al., 2019). Across all the studies included in the review, there was only one instance of medication being increased. This was due to more appropriate medication being introduced 11 months after PBS (McClean et al., 2007).

3.Improvements in Quality of Life

Quality of life refers to a person’s well-being and different domains encompass this depending on the outcome measure used. For instance, the Quality of Life Questionnaire (Schalock, Keith, Hoffman, & Karan, 1989) includes choice and control, community inclusion, and equity. Quality of life was included as an outcome in nine of the articles in the review and was reported as both quantitative and qualitative data.

3.1 Positive Enhancements to Mental Health and Wellbeing

Mental health and well-being were outcomes across five of the studies. Within the quantitative studies, this was assessed using the Mini PAS-ADD (Prosser et al., 1998) and the HoNOS-LD (Roy, Matthews, Clifford, Fowler, & Martin, 2002) outcome measures. Mental health improved for participants who received support from the intensive community intervention service, and significant reductions in mean HoNOS-LD scores were observed post-intervention. However, it was unclear how long this was maintained (Lewis et al., 2021). Similarly, McKim and Samuel (2021) showed a reduction in depression, anxiety, and hypomania scores for three of the four participants 26 weeks and 76 weeks after the intervention was implemented. Support with emotions was highlighted as an element of PBS. Participants shared that they were listened to by staff as a way to manage difficult situations and regulate emotions (McKenzie et al., 2018b):

> *"Yeah, I talk to staff now. When I feel agitated. I didn't used to that years ago. I just tell them I'm feeling a bit like… angry and stuff like that."*
>
> *(McKenzie et al., 2018b, p.244).*

3.2 Relationships with Staff and Families

Changes in relationships were reported across four studies. This included gaining positive relationships with staff and with their families. Development of connections and relationships with staff were valued where the staff made an effort to get to know the person and be reliable and responsive to their needs:

"I feel like she's a friend now because when she comes around she always makes me smile. She stops me looking on the black side of things"

(McKenzie et al., 2018b, p. 243)

This was echoed from the staff's perspective on relationships. After staff teams received support from the intensive support team, they reflected that rapport had improved amongst permanent members of staff:

"Intensive Interaction helped build and cement a relationship with Graham. He felt that people were with him"

(McKim & Samuel, 2021, p.132)

Improvements in relationships also included the relationship between family and carers and support staff. Family and carers reported the importance of taking a "central role" in their child's care and appreciated staff involving them within PBS planning and implementation:

"Communication between staff and relatives, and all were appreciative of regular and open contact, being listened to."

(McKenzie et al., 2018a, p. e61)

Improvements in relationships with family were noted for one individual who was able to visit his family overnight one night a week; prior to the PBS intervention, he had limited contact with his family (McClean & Grey, 2012). McKenzie, Murray and Martin (2021) focused on the use of PBS throughout the Coronavirus pandemic and how this impacted the implementation of support. It was noted in one subtheme that social relationships, particularly with families, were greatly impacted by the pandemic but that the staff team actively tried to replicate these connections in alternative ways:

"So we are looking at different ways we can get family involved…now that we have Skype and we have clients who've bought iPads"

(McKenzie et al., 2021, p. 1092)

3.3 Additional Activities and Occupation in the Community

An important area included in the improvement of quality of life outcomes encompasses additional leisure activities and occupations in the community. Increased engagement in "meaningful activity" increased after PBS implementation; however, this was not significantly more than the control group (McGill et al. 2018). More involvement in community-based activities was noted in a few studies. For one person, this involved taking part in daily trips to the shop, but it took three years to build up to this (McClean & Grey, 2012). Involvement in meaningful activities as part of the PBS support plan for some participants included hobbies and leisure activities:

"They've took me on walking groups, they've took me swimming"

(McKenzie et al., 2018b, p. 244)

In another study, the intensive support team reported the return of previous community involvement for one person after behaviours that challenge were reduced (McKim & Samuel, 2021). McKenzie et al. (2021) noted that the pandemic restrictions impacted the community-based activities the service users were able to be involved in, but the staff tried to replicate these activities within the home:

"Say a person has an art session or a cookery session, that's normally out in the community, they've created that structure at home"

(McKenzie, Murray & Martin, 2021, p. 1092)

Concerning occupation opportunities, one study found improvements in the home environment support and improvements in occupational engagement with significant improvements in motivation for occupation, the pattern of occupation, and the environment post-PBS intervention from the intensive community intervention service (Lewis et al., 2021). Two participants secured supportive employment and another commenced a computer training course after receiving PBS support in the community (McClean et al., 2007). Supported employment services were involved in the PBS planning for four adults with intellectual disabilities and behaviours that challenge (West & Patton, 2010). The support plan included training and support to scaffold the participants to independently perform occupational tasks, including distributing flyers and washing tables. All participants were supported to perform the tasks independently, and when involved in this process, there was a complete absence of behaviours that challenge.

4.Changes in the Extent of Support Required

The implementation of PBS within services and the reduction of behaviours that challenge consequently reduced the need for as much staff support. This was welcomed by people with intellectual disabilities and saved the services money. Where support remained, the quality of the relationships improved.

4.1 Support Reduction for Behaviours that Challenge

Support was reduced for some individuals due to the reduction of behaviours that challenge and more appropriate allocation of staff support. For example, staff allocation was reduced overall for participants by 12.3% in day services and 7.2% in residential services after PBS was implemented (McClean et al., 2012). A reduction in staff support in the living environment was seen as a benefit to people with intellectual disabilities when they discussed beneficial physical and psychological environments:

> *"They don't have loads of staff here. They don't have many clients. That makes it easier for me to, err, talk to people. I can't live with loads of people because that agitates me…"*
>
> *(McKenzie et al., 2018b, p. 245)*

A reduction in staff allocation led to cost savings within services. One study demonstrated a reduction in revenue costs over 18 months for five adults by 28%, although this was greatly skewed by large cost savings for one individual due to less intensive staff support needed (McClean et al., 2007). Effective behaviour support plans also facilitated a reduction in crisis support admissions. In one study, the participants were supported by callouts from the behaviour support team, and during the twenty-four months that data was recorded, only one participant required crisis respite and this was preceded by a change in medication (McClean et al., 2012).

Independence was increased for occupational tasks and living skills. For instance, West and Patton (2010) illustrated that all the participants became independent after 15 sessions of training and support facilitated by a positive behaviour support plan. People with intellectual disabilities were supported to learn and develop independent living skills as part of the PBS support, and they spoke about wanting to live as independently as they could and have greater choice and control:

"For me, when I go out places, I sometimes like to have my own independence…I've been living at my mam and dads for too long, nearly 30 years. I want my own, erm, breathing space. So I can go to the door and ask people if they want to come round".

(McKenzie et al., 2018b, p. 245)

4.2 Increased Support Networks and Quality of Support

The quality of staff support improved post-intervention, as measured by the Active Support Measure (Mansell & Elliott, 1996; Mansell & Beadle-Brown, 2005). Mean Active Support Measure scores significantly increased in seven out of nine settings that received PBS service improvement, compared to the control group (McGill et al. 2018). Active support was recorded for one person with behaviours that challenge as 70% at the 10-year follow-up (Toogood et al., 2011). This is considered a good level of active support (Bigby, Bould, Iacono, Kavanagh & Beadle-Brown, 2020) but this was not compared to a pre-intervention measure so it is unclear if this was an improvement.

Support also improved when family members were involved in the delivery of PBS. Family members highlighted the importance of having a "central role" in their family member's care in ensuring that PBS interventions were person-centred:

"Some of the things that we suggested to put in place proved to work. Cos, obviously, we know Michael" (McKenzie et al., 2018a, p. e61)

Despite their involvement in PBS interventions, family members reported not receiving PBS training but felt that they were already supporting in line with the PBS approach:

"Although we didn't think of it as PBS with the name… in a way, that's what we were doing anyway" (McKenzie et al., 2018a, p. e61)

As support improved in the complex behaviour service group the average social care cost increased by 51%, this included the cost of supported living, day-care provision and training, as compared to the control group (Inchley-Mort et al., 2014). It was hypothesised that the increase was due to the service reviewing clients' social care packages and new support being pursued. McKenzie et al. (2021) suggested that the opportunity to focus more on active support came as a result of the pandemic as the staff team transformed mundane tasks into more meaningful activities for the residents:

> *"On the majority of levels, it's been a positive impact, I suppose more so in respect to active support which obviously leads into the PBS".*
>
> *(McKenzie et al., 2021, p. 1092)*

5.Elements of Positive Behaviour Support Which Assisted Changes in Outcomes Post-Implementation

Although the studies included in the review did not focus explicitly on the effectiveness of PBS and the elements responsible for positive outcomes, the resulting increase in knowledge and understanding was attributed to the improvements. PBS was also contrasted with previous negative experiences of care.

5.1 Increased Understanding of People with Behaviours that Challenge

The positive impact of PBS was noted in some of the literature by staff, family, and carers. Seventy-two staff from social care settings where PBS was implemented completed a questionnaire evaluating the intervention's impact, and 68% reported PBS having a positive impact (McGill et al., 2018). Families and carers noted that PBS led to improvements in behaviours that challenge and attributed it to the increased understanding and improved support:

> *"He very rarely has episodes of challenging behaviour and it's mainly because we feel he has been supported in the right way delivered in the right way; it works"*
>
> *(McKenzie et al., 2018a, p. e60)*

Furthermore, people with behaviours that challenge shared the positive outcomes of PBS on their lives, particularly the reduced use of restrictive practices and restraint:

> *"I've came off my CTO [community treatment order]. That's never happened. I've never come off a section or a CTO before. I get out more… I go to college."*
>
> *(McKenzie et al., 2018b, p. 246)*

Elements of PBS that contributed to improvements in levels of behaviour that challenge and quality of life were discussed in some of the studies. One component of the support that was highlighted as important was the values held by the staff. Family and carers emphasised the importance of respect, dignity, care, engagement and self-determination:

> *"[treat him] like a human being. Treat him like he matters and like he has a life"*
>
> *(McKenzie et al., 2018a, p. e59).*

In addition, the staff had a high level of technical knowledge of PBS and competence in using the framework. Family and carers valued this and staff individualised PBS to the person they were supporting. Moreover, having an in-depth knowledge of the person with behaviours that challenge can be translated into concrete care plans and strategies:

"During that period they would do visits … they'd taken everything into considerations, then put everything into place then moved them."

(McKenzie et al., 2018a, p. e59).

Periodic service reviews measured the proportion of behaviour support plans implemented within services, McClean et al., (2007) reported implementation increases to 95% for two participants and 80%, 74% and 48% for the other three participants. It was noted how the pandemic helped with the implementation of PBS and a better understanding of behaviours that challenge as staff had more time to train, implement PBS plans and evaluate the outcomes:

"It probably would have taken us months and months to train people in activate support and get them to understand the value of engagement, whereas they've done this in a week"

(McKenzie et al., 2021, p. 1094)

5.*2 Contrast with Negative Experiences*

Positive outcomes of using PBS were contrasted with negative experiences of care that many people and their families experienced previously. People with behaviours that challenge described negative experiences they had endured in the past and how this exacerbated their difficulties:

"When they restrained me. I've hurt staff trying to get out of the locks and stuff like that"

(McKenzie et al., 2018b, p. 246)

Families and carers described the power and control of the systems that were providing support for their loved ones. They described feeling powerless, particularly concerning restrictive practices and restraint, and hypothesised that this increased the frequency of behaviours that challenge:

"If I was incarcerated somewhere… or restrained, well I'd be challenging"

(McKenzie et al., 2018a, p. e60)

Families and carers shared their historical negative experiences of trying to get good quality support for their loved ones, before PBS support. They described a "battle" and having to "fight" to obtain the right support against the weight and power of the system. This resulted in support that was one-sided:

"They [professionals] knew better than we did. That was their attitude. They were trained professionals and we were just the parents"

(McKenzie et al., 2018a, p. e60)

The implementation of PBS and strategies to support the person with their behaviour led to the reduction of restrictive practices. For instance, Webber et al. (2017) recorded a reduction in the use of mechanical restraints for one person six-months after PBS was implemented. This was reduced to zero restraints after 10 months and they were no longer used when he displayed behaviours that challenge.

Discussion

Overview of the Findings

This review aimed to investigate the outcomes of implementing PBS to support adults with intellectual disabilities and behaviours that challenge. The results of the review emphasise several positive outcomes of PBS and indicate elements of PBS that contribute to the post-intervention changes. Twelve of the studies included in the review discussed the reduction of the frequency and severity of behaviours that challenge, particularly self-injurious behaviour, aggression, stereotypy, and irritability after PBS was implemented. This is similar to literature reviews of outcomes after staff PBS training, which demonstrated reductions in the frequency of behaviours that challenge (MacDonald & McGill, 2013; Mahon et al., 2021). Two studies reported an increase in behaviours that challenge after the intervention; despite the increase, there was a greater understanding of the factors contributing to the behaviour (Conway et al., 2019; Webber & Patton, 2010). Medication reduction, particularly the reduction of antipsychotic medication, was recorded in some studies. This was often facilitated by an increase in access to medication reviews, and this was incorporated into some PBS plans to reduce medication as part of the intervention (McClean et al., 2007; McKim & Samuel, 2021; Toogood et al., 2011). Alternatively, the reduction of medication was a result of the reduction of behaviours that challenge (Conway et al., 2019). This supports the aim of Stopping Over Medication of People with Learning Disability (STOMP) to reduce inappropriate prescribing of psychotropic medication and the use of non-pharmacological methods as the first line of intervention (NHS England, 2016; NICE, 2017). Where medication was increased, this was due to the individual being supported to access more appropriate medications, including for mental health difficulties (McClean et al., 2007). However, research suggests medications should be prescribed after a thorough assessment and formulation of a person’s circumstances and provide a rationale for their use and be used alongside non-pharmacological interventions (Deb, Sohanpal, Soni, Lentre & Unwin, 2007).

The research included information on the changes to the quality of life post-intervention, including improvements to mental health and well-being. This emphasised the values of PBS in improving quality of life that was not reported in previous reviews (MacDonald & McGill, 2013). However, it should be acknowledged that some studies excluded participants with “severe mental health conditions” from the sample. Therefore, some mental health experiences may be underrepresented within the review. Relationships with staff and family members strengthened throughout the PBS process. This may be due to an increased understanding of the person and more opportunities to nurture relationships (Carr et al., 2002). Families and carers also play a vital role in supporting their loved ones, and the relationship between the families and the staff is important at every stage of PBS.

The research showed that as PBS was introduced and the support improved, there was a reduction in the need for staff support. Staff allocation, restrictive practices, and the need for services such as crisis support were also reduced. This supports the role of PBS in decreasing the use of restrictive practices for people with intellectual disabilities (PBS Academy, 2015). Two studies demonstrated a reduction in social care costs after the implementation of PBS (Inchley-Mort et al., 2014; McClean, Grey & McCracken, 2007). A previous literature review conducted by LaVigna and Willis (2012) found PBS to be cost-effective. However this systematic literature cannot conclude this as the reduction was only reported in two studies and in one study it was skewed by significant savings for one individual (McClean, Grey & McCracken, 2007). The quality of support provided by services also improved, and this may be linked to PBS facilitating an increased understanding of behaviours that challenge. The core values of PBS were highlighted, such as respect and dignity.

People with behaviours that challenge recalled increased involvement within the community and “leading a normal life” as important elements that should be included in PBS. This supports the normalisation philosophy that PBS is built upon (Carr et al., 2002). More meaningful activities and the opportunity to start training or employment were large contributors to improved quality of life. Throughout the literature, there was a contrast with negative experiences, including power differentials, lack of control, and restrictive practices. For too many people with intellectual disabilities, they have had negative experiences with services and a “fight” to gain the correct support was highlighted in the literature.

Strengths and Limitations of the Systematic Literature Review

The research question was explored by including both qualitative and quantitative research studies. This enabled a broad range of research papers to be included in the review, incorporating the experiences of carers and people with intellectual disabilities. The studies were mostly conducted in the UK and Ireland, therefore there is a high homogeneity and PBS was likely understood and applied similarly. There was a variation in the settings PBS was implemented in and the services implementing PBS, but it was implemented only implemented in community settings. Therefore, the findings are not applicable to implementing PBS in inpatient hospitals or the use of PBS in non-western countries.

Only one study included in the review explored the experiences of PBS from the perspective of people with intellectual disabilities and behaviours that challenge (McKenzie et al., 2018b) which had a relatively small sample size of seven participants. The other studies were from the perspective of care staff, family carers or the services implementing PBS as they were interviewed or completed the outcome measures. Therefore, the conclusions related to the outcomes of implementing PBS are mostly based on the perspectives of those who implement PBS rather than those it is being implemented to support and does not represent their perspectives fully. Furthermore, there is an innate bias of people implementing PBS to suggest that the outcomes are positive.

Within the studies, a variety of outcome measures were used to measure concepts such as behaviours that challenge, quality of life and support provided by services. Therefore, there will be a variation in the concepts the studies aimed to measure. For instance, when measuring quality of life, McGill et al. (2018) only used one measure of ‘meaningful activity’ (EMAC-R), whereas Lewis et al., (2021) used five measures of quality of life (the GCPLA, the QoLC, the HONOS-LD, the REIS-SF and the MOHOST). Therefore, various elements of quality of life were measured. Similarly, the methods for measuring behaviours that challenge also varied from qualitative reports from staff and family, structured interviews and quantitative measures of frequency and severity.

The quality of the literature in the review is mixed, according to the MMAT quality assessment tool and due to this only tentative conclusions can be drawn. In quantitative studies, this was due to incomplete outcome measures and low control for potential confounding variables. For instance, across the studies, some included people with comorbid mental health difficulties and others excluded this. Furthermore, where mental health difficulties were included, it is unclear how this is accounted for in the analysis. The quality of qualitative studies was overall higher, however, the use of quotes to support the themes was limited, particularly McKenzie et al. (2018a), McKim and Samuel (2021). Therefore the analysis process and the findings are not illustrated explicitly (Eldh, Årestedt & Berterö, 2020) and the findings are based on a small pool of quotations from participants.

Clinical Implications and Future Research

Within healthcare, it is important to have evidence-based practice as it supports the implementation of practices that lead to better patient outcomes (Fineout-Overholt, Melnyk & Schultz, 2005). The current systematic literature review adds to the growing literature base supporting the use of PBS and the guidance that recommends PBS as the best practice. This review highlights the outcomes of implementing PBS for people with intellectual disabilities and behaviours that challenge and the services and carers who support them. Improvements to quality of life were highlighted as a key outcome of implementing PBS, and this review demonstrated the usefulness of including occupation and skills training to improve quality of life. This connects to the value of building stakeholders' skills and opportunities in the PBS framework. Other literature has also suggested the importance of meaningful occupation for health and well-being and may reduce the frequency of behaviours that challenge (Ball & Fazil, 2013). Therefore, occupation and building skills should be considered when creating PBS plans.

The overmedication of people with intellectual disabilities, particularly the use of antipsychotics, has been a concern since the 1970s and programmes to reduce overmedication such as STOMP (Branford, Gerrard, Saleem, Shaw & Webster, 2019) have been created. Despite this, there are more recent concerns about the overuse of antipsychotics highlighted by the events at Winterbourne View. The current review highlighted how medication reviews were more frequent as part of the implementation of PBS, as compared to control groups, supported medication reduction and sometimes the introduction of more appropriate medications. This highlights the usefulness of reviewing medication as part of the PBS plan periodically, to monitor the use of antipsychotics and the side effects.

Finally, PBS was contrasted with previous negative experiences for people with intellectual disabilities who display behaviours that challenge, particularly the use of restraints and being in inpatient hospital environments. This highlights the long-lasting negative impact restrictive practices have on people with intellectual disabilities and behaviours that challenge, despite now experiencing PBS, which overall had positive outcomes on their quality of life, reductions in restrictive practices and improved quality of relationships. Therefore, there needs to be improved support for those who have experienced restrictive practices and also their families and carers who felt ‘powerless’ and ‘out of control’ to the system. This may include ‘post-incident support’ and also therapeutic interventions.

As highlighted above, future research should further explore the experiences of people with intellectual disabilities and behaviours that challenge. It is imperative to hear their perspectives on how PBS is used to support them, the usefulness of PBS and the extent of their involvement in PBS. This would ensure PBS is more person-centred, a key value of the PBS framework, and ensure it is designed in the best way to support people with intellectual disabilities. It is particularly important when researching areas linked to the use of restrictive interventions where people with intellectual disabilities who display behaviours that challenge have disproportionally been affected (Fitton & Jones, 2020), and the detrimental impacts of this. Research suggests that the most complete representations of people with intellectual disabilities views in research are gathered through semi-structured interviews and photographic intervention (Ottmann & Crosbie, 2013).

Conclusion

Despite the limitations of the literature, the review generated themes around positive outcomes of implementing PBS to support people with intellectual disabilities and behaviours that challenge. This included improvements to quality of life, improved quality of relationships, reductions in medication use, and reduced behaviours that challenge. This reflects the core values and philosophical principles at the heart of PBS and shows that these standards are exhibited in the outcomes of services. Future research should explore the experiences of people with intellectual disabilities from a variety of services and with a range of abilities. Further evidence on the implementation of occupation and skills training as part of the PBS process is also recommended.

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Part Two: Empirical Paper

This paper is written in the format ready for submission to the Journal of Applied Research in Intellectual Disabilities.

Please see Appendix C for submission guidelines.

Exploring Experiences of Working within a Positive Behaviour Support (PBS) Framework and how this Influences Attitudes, Perceptions, and Values towards people with Intellectual Disabilities who Present with Behaviours that Challenge.

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Abstract

Background: The research aimed to explore the experiences of health care assistants who worked within a PBS framework in inpatient services; exploring how their attitudes and behaviours related to the assumptions of PBS. The attributions held by healthcare staff impact the helping behaviour offered to support people with intellectual disabilities and behaviours that challenge.

Method: Six healthcare assistants were recruited using purposive sampling from an inpatient service. Semi-structured interviews were conducted and data were analysed using interpretative phenomenological analysis.

Results: Three superordinate themes were developed**:** 'Understanding Behaviours that Challenge', 'Using PBS as a Health care Assistant' and 'Relationships'.

Conclusions: This research highlighted the perceptions and attributions made by health care assistants, the implementation of PBS and the importance of relationships within the MDT and with patients. The positives of working with people who display behaviours that challenge and the difficulties of working with risk and restrictive interventions were explored.

Keywords: Positive Behaviour Support, Behaviour that challenges, Health Care Assistants, Experiences, Inpatient, Interpretative Phenomenological Analysis.

Introduction

Behaviours that challenge (BTC) can be conceptualised as behaviour "outside of the cultural norm" that "occur at such a frequency, severity or for a long period that they have social consequences including harm to self, harm to others and exclusion from communities" (Emerson & Einfeld, 2011, p.4). Behaviours include self-injury, aggression, destructiveness and inappropriate social or sexual behaviours and are observed in around 10-15% of adults with intellectual disabilities (Emerson et al., 2001). In addition, people with intellectual disabilities are more likely to experience mental health problems than the general population, with an estimated prevalence of around 40.9% (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). Moreover, there is an association between experiencing mental health difficulties and exhibiting behaviours that challenge (Felce, Kerr & Hastings, 2009). The NHS Long Term Plan (NHS England, 2019) highlighted the prioritisation of the improvement of community-based support. The Transforming Care Report (Department of Health, 2012) detailed actions which included ending inappropriate placements to ensure people with behaviours that challenge are supported locally and in the community where possible. Despite this, the Assuring Transformation Collection 2022 report revealed that 2,005 people with intellectual disabilities were in inpatient care, with more discharges than admissions, and 3,565 reported instances of restrictive interventions (NHS Digital, 2022). Moreover, literature examining inpatient admissions for people with intellectual disabilities illustrated that behaviours that challenge are the most common reason for admission (Oxley, Sathanandan, Gazizova, Fitzgerald & Puri, 2013).

Positive behaviour support (PBS) is a holistic framework used to support individuals with behaviours that challenge and enhance their quality of life (Gore et al., 2013). PBS can be implemented across various settings, including in the community and inpatient hospitals, and implemented by a single practitioner or through system-wide approaches (PBS Academy, 2015). PBS effectively supports severe behaviours that challenge that are frequent and high risk (LaVigna & Willis, 2012) and is associated with the reduction in restrictive techniques in inpatient settings (Richardson, Webber & Lambrick, 2020). Implementing a PBS plan in inpatient services requires several factors, including comprehensive staff training, collaboration from the multidisciplinary team, and consistency in implementation across staff (Hamlett, Carr & Hillbrand, 2016).

Literature on care staff working with adults with intellectual disabilities and behaviours that challenge has primarily focused on the negative impacts of working in this area. For instance, Chung and Harding (2009) found the more care staff perceived behaviours as challenging the more they experienced emotional exhaustion and diminished feelings of personal accomplishment (Chung & Harding, 2009). Additionally, the more behaviours that challenge staff experienced the more likely they were to experience burnout (Mills & Rose, 2011). The risks associated with working with behaviours that challenge adversely affect care staff. Campbell (2011) found that nurses experienced emotional distress and anxiety related to the anticipation of violence against them. Moreover, among care staff, health care assistants are more likely to be involved in incidents of aggression as their role is more "hands-on" (Vanderslott, 1998).

Aggressive behaviours were not always perceived negatively; Whittington and Higgins (2002) highlighted that mental health nurses perceive moderate levels of aggression as a cathartic and therapeutic relief from distressing physical and psychological tension, but greater levels of aggression reduce the likelihood of positive evaluation. Similarly, staff have expressed positive attitudes towards residents with behaviours that challenge, including confidence, empathy, and wanting to help, despite the work-related stress they experienced (Bell & Espie, 2002). There has been an increase in the recognition of the factors contributing to a reduction in burnout in care staff working with behaviours that challenge including social support in work, internal locus of control, and involvement in decision-making (Gray-Stanley & 2011).

A maintaining factor of behaviours that challenge, suggested in Hastings et al's. (2013) framework, is the behaviours of those around them. Carers create the context and environment that maintain and exacerbate behaviours, for instance, not providing enough social contact or creating aversive interactions. Hastings et al. (2013) highlighted the influence of a carer's beliefs, attitudes, and emotions, as well as the wider societal and political context, which contribute to maintaining behaviours that challenge. The attributional model of helping behaviour (Weiner, 1980) stated that the attributions made about a behaviour influence the emotional reactions and helping behaviours of individuals. When carers attributed internal cause and controllability to behaviours that challenge they were more likely to experience negative affect and lower sympathy, which led to avoidance behaviour and less intention to help (Hill & Dagnan, 2002). Carers attributed stability to self-directed behaviours such as self-injury and were more likely to support than outer-directed behaviours such as aggression or damaging property, as they attributed more control (Stanley & Standen, 2000).

National Institute for Health and Care Excellence (NICE) guidance recommended that staff who provided direct support to people who display challenging behaviours must have competency using PBS (NICE, 2018). Training has positively improved the application of PBS within services, including improved self-efficacy, increased understanding, and enhanced ability to formulate the functions of behaviour, as well as greater skills in developing and implementing a PBS plan to benefit the service user (Stocks & Slater, 2016). Furthermore, a review of care staff using PBS across a variety of settings found positive changes in skills, confidence, knowledge, attributions and emotional responses (MacDonald & McGill, 2013). However, PBS training studies often do not include measures of behaviour change. Therefore, it cannot be assumed that this resulted in positive changes in helping behaviour, also known as “train and hope” (Stokes & Baer, 1977). Moreover, the changes to staff attributions after training may not be long-lasting; Lowe et al. (2007) showed that positive changes in attribution returned to baseline at the one-year follow-up on ratings of the Challenging Attribution Scale (Hastings, 1997).

The use of PBS plans within inpatient services has been evaluated and found to be poorly implemented due to nurses' overfocussing on managing behaviours, selectivity around which patients received a plan, and a lack of understanding of the principles of PBS (Clark et al., 2020). Other barriers to implementing person-centred PBS in community-based services included fears of getting hurt and taking risks; however, facilitators of PBS work were close relationships between support staff and the focus on the person, which promoted the development of empathy and understanding (Bambara et al., 2016).

Rationale

The drive for the reduction of restrictive practices within mental health services, particularly in inpatient services, has been accompanied by the increased use of PBS to provide proactive and preventative care for individuals who display behaviours that challenge (Department of Health, 2014). Furthermore, there is a desire to ensure inappropriate placements in hospitals are ended and patients are supported appropriately in the community rather than inpatient care, which by nature is restrictive (NHS England, 2019). However, few research papers have explored the use of PBS within inpatient intellectual disability services, and when investigated it was found that PBS was often poorly implemented (Clark et al., 2020).

Research on staff experiences of using PBS has focused on their experiences of PBS training. Such research has not reflected long-term changes in the care staff provide (Lowe et al., 2007), with one paper stating that staff found no benefit of training in PBS versus treatment as usual (Hassiotis et al., 2018). Investigating the use of PBS from the perspective of staff is important as their attitudes, beliefs and perceptions of behaviours that challenge affect the maintenance of PBS and the implementation of PBS (Hastings et al., 2013; Clark et al., 2020). Previous research has discussed the role of those who create PBS plans and lead the implementation of the PBS framework such as psychologists and nurses (Savarimuthu, 2020; Scior, Brown, Gore, Morris & Armstrong, 2017).

Exploring the experiences of healthcare assistants (HCAs) who work in inpatient services would support the understanding of how PBS is implemented as they work directly with patients and deliver PBS plans. It is hoped the research will amplify the voices of HCAs who are more likely to experience the negative impacts of working with behaviours that challenge such as burnout and emotional distress (Mills & Rose, 2011). Furthermore, exploring HCAs' attitudes, perceptions and beliefs would illuminate if the care provided is consistent with the core PBS values. Additionally, it would highlight factors that facilitate the implementation of PBS and the potential barriers and implications for staff, patients and the service.

Research questions

How do healthcare assistants experience supporting people with behaviours that challenge within a PBS framework in intellectual disability inpatient services?

Secondary aims:

What are the attitudes, perceptions, and beliefs of health care assistants working with people with intellectual disabilities and behaviours that challenge within a PBS framework in intellectual disability inpatient services?

Methods

Design

The research used a qualitative design to gather rich details of the participants' experiences. Data was collected using semi-structured interviews and an interview schedule consisting of open-ended questions on the participant's experiences of working with people with behaviours that challenge, working within a PBS framework, and explored the attitudes and values around their work (see Appendix N). This was analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009).

Participants

Purposive sampling was employed within a local NHS inpatient service that applied the PBS framework within the service. PBS was used regularly with all patients, including assessment, interventions, and regular reviews. PBS training was delivered by PBS coaches over two days for all staff and included topics on values, factors contributing to behaviours that challenge, and the use of the PBS approach and techniques. The inpatient service had several PBS coaches, and the implementation of PBS was overseen by the clinical psychologist. A homogenous sample of health care assistants (HCA) were recruited who met the inclusion criteria: a minimum of six months of working in the service; experience using PBS not limited to one individual, and had received PBS training. These inclusion criteria were used to ensure the participants had a depth of experience using PBS. The participants had to be over the age of 18 and be English speakers. Six participants took part in the study (see Table 1 for participant demographics).

Procedure

Ethical approval was granted by the University Research Ethics Committee and the Health Research Authority (see Appendix H) to recruit NHS staff. Links were made with a clinical psychologist within the service, who acted as the field supervisor and distributed the study information flyer (see Appendix J). The potential participants contacted the lead researcher via email. The lead researcher sent the information sheet containing more detailed information on the study (see Appendix K). If the potential participants showed a continuous interest, the demographic questionnaire (see Appendix M) and consent form (see Appendix L) were completed before arranging a time to meet for the interviews. The lead investigator conducted six interviews with durations between 21 minutes and 50 minutes. The interviews were face-to-face at the inpatient unit (n = 5) or online via Microsoft Teams due to COVID-19 (n = 1).

Table 1. Participant Demographics.

Participant pseudonym	Age (range)	Gender	Ethnicity	Length of time working with people with intellectual disabilities	Length of time working in the service	Hours of PBS training	Who delivered PBS training	Length of time using PBS
Dave	25-34	Male	White British	6 years	2 years	5+ hours	In-house & accredited	2 years
Roger	55-64	Male	White British	8 years	7 years	5+ hours	In-house	3 years
Jenny	45-54	Female	White British	26 years	16 years	5+ hours	In-house	4 years
Emma	25-34	Female	White British	4 years	4 years	5+ hours	In-house & accredited	4 years
Yelsel	45-54	Female	White British	24 years	3 years	5+ hours	In-house	3 years
Mary	45-54	Female	White British	35 years	6 years	5+ hours	In-house	4 years

Ethical considerations

The lead researcher met with health care assistants who helped to develop the information sheet and interview schedule. Before beginning the interview, consent was checked and it was reiterated that the interview could be terminated and they could withdraw at any point. It was made clear that any safeguarding issues would have to be escalated if the researcher had concerns. Participants were advised that they did not talk too specifically about individuals they had supported to preserve the confidentiality of the service users and instead talk broadly about their experiences. At the end of the interview, participants were debriefed. The interviews were audio-recorded on an NHS laptop and transcribed verbatim. The recordings were then deleted. During transcription, any identifiable information was anonymised, and participants were given a pseudonym that they chose.

Data Analysis

The transcripts were analysed using IPA according to the guidance posed by Smith & Nizza (2021). IPA was selected as the research was interested in the participants' experiences and understandings of working with behaviours that challenge using PBS in inpatient services. The interpretative and phenomenological aspects of IPA allowed for a rich analysis of participants' involvement in a phenomenon and how they made sense of this (Smith, Flowers & Larkin, 2009). The double hermeneutic process of IPA was applied in this study to explore the participant’s understandings of working with behaviours that challenge and using PBS and also the researcher's interpretations of how the participants understood these experiences, particularly looking at their beliefs, perceptions and beliefs. Furthermore, IPA was appropriate for the homogeneity of the sample due to the theoretical underpinnings of ideography. HCAs offered a perspective of PBS and challenging behaviour that has not been explored in other research; they directly implement PBS plans and have close working relationships with people with intellectual disabilities who display behaviours that challenge on inpatient units.

The analysis included key IPA characteristics including idiographic, inductive and interrogative analysis with varying levels of interpretation (Smith, 2004). Analysis began, alongside data collection, by reading the transcript and creating exploratory notes that involved descriptive, linguistic, and conceptual commenting (Spiers & Riley, 2019). Exploratory statements were then formulated as a concise summary of what emerged in the section of the data. These were collated in a table, printed and cut out so that the statements could be clustered to synthesise and organise the data. The clusters were transferred to a table and then converted into a table of Personal Experiential Themes (PETs) where the clusters were named and references to direct quotations were added to ensure the PETs were grounded in the data. Once each transcript had a corresponding table of PETs, they were printed out and cross-analysed, looking at common patterns and idiosyncratic differences, to generate Group Experiential Themes (GETs). Appendix O includes an example of this process and Appendix B shows the epistemological position of the researcher. The results section followed the "four markers of high quality" outlined by Nizza, Farr and Smith (2021), and was written as an 'unfolding narrative' which attended to the convergence and divergence of experiences and included the close analytic exploration of participant's words to make sense of their experiential account of events (Nizza, Farr & Smith, 2021).

Quality Assurance and Reflective statement

The research supervisor and a peer researcher reviewed the analysis process, including the exploratory statements and group experiential statements that were created, and the narrative to verify the quality of the analysis and to ensure the results were grounded in the data. As a result of the interpretative and double hermeneutic nature of the analysis, the researcher's positions should be acknowledged. The researcher is a white British female trainee clinical psychologist from the North East of England. The researcher had personal experience of a family member who worked as a health care assistant who supports people with intellectual disabilities in the community. The researcher used research supervision and a reflective diary to reflect upon the social and cultural context and personal preconceptions throughout the research process (see appendix A). Furthermore, the impact of being a trainee psychologist interviewing HCAs on a framework that is regularly led by psychologists was reflected upon.

Results

Verbatim quotes are included throughout the results section to ensure themes are grounded within the data and reflected the participant's experiences. The quotes include ellipses to represent text that was removed to ensure the participant's quotes are succinct. The full quotes can be found in Appendix P and additional supporting quotes can be found in Appendix Q. People with intellectual disabilities and behaviours that challenge were often referred to as patients due to the context of the inpatient hospital. This language is used within the findings for continuity. The analysis produced three superordinate themes and ten subordinate themes (see Table 2).

Table 2. Superordinate Themes and Subordinate Themes

Superordinate Themes	**Subordinate Themes**
1. Understanding Behaviours that Challenge	1.1 Developing a Holistic Perspective
	1.2 Discourses, Beliefs and Attitudes
	1.3 Making Sense Through the Analysis
2. Using PBS as a Health Care Assistant	2.1 The Involvement of HCAs in the Development and Implementation of PBS plans
	2.2 PBS Intertwined in HCA Work
	2.3 Successes and Positive Challenges
	2.4 The Challenges of Working with BTC and Risk
3. Relationships	3.1 A Consistent, Cohesive and Persistent MDT Approach
	3.2 Therapeutic Relationships
	3.3 Patients Should be Involved More but There are Barriers

1. Understanding Behaviours that challenge

This superordinate theme is comprised of three subordinate themes that reflect the participant's perceptions of behaviours that challenge. This includes a comparison of their previous perceptions in the community compared to in the inpatient environment. Furthermore, the participants considered various factors contributing to behaviours that challenge, including societal discourses and HCA's beliefs and attitudes. The HCAs described their understanding through the lens of behavioural analysis and developing hypotheses, a major component of the PBS framework.

1.1 Development of a Holistic Perspective

Two of the participants described a progression of their views of behaviours that challenge. Roger shared that behaviours that challenge initially shocked him as this was not something he had seen in his work in community services; "*initially it was like woah, what's going off?"* (Roger). Similarly, Dave reflected on his previous understanding of behaviours that challenge as missing an in-depth analysis of the factors contributing to them "*if someone was acting in a challenging way I'd probably have quite a two-dimensional way of looking at it and think they're acting this way because that's who they are"* (Dave).

Their initial perceptions of behaviours that challenge were something that was directed towards them and part of who the person was; illustrating that they perceived the patients as having an internal locus of control. When the participants developed an understanding of the possible triggers, through reading many PBS plans, they felt less targeted and safer. This was captured in a quote from Roger:

> *"It was fine because you understood, well, in general, that it wasn't a targeted thing at you in general, it was a reaction to their environment or to particular stressors or triggers erm,*

> *things that were out of their control and it was just their reaction to it so as I say that's probably why I didn't feel at risk or unsafe"* (Roger)

Participants also noticed that this change was accompanied by an increase in empathy and compassion for patients displaying behaviours that challenge; "*now I'd understand and I can see it from a whole other perspective…. more empathy and compassion" (Dave).*

1.2 Discourses, Beliefs and Attitudes

Dominant discourses about people with behaviours that challenge and people with intellectual disabilities were identified by the participants. One discourse Jenny observed was the pathologizing of the expression of emotion with people with intellectual disabilities in inpatient services. This dominant discourse of behaviours as "challenging" was something Jenny positioned herself against. Jenny stated her disagreement and she normalised the presence of behaviour as an articulation of their emotions, typically those causing distress:

> *"They are allowed to get angry … to get upset and who are we to say no you can't? But as soon as that person … gets annoyed or gets upset it's ooo it's a behaviour, ooo it's a challenge, it's not it's an expression of how they are feeling" (Jenny)*

Jenny suggested that this dominant discourse was filtered into the actions of staff and patients were not "*allowed*" to express emotions through their behaviour because it may be perceived as challenging. She also mocked this dominant position, "*ooo it's a behaviour*", to illustrate how she was opposed to this perception.

Emma considered the pressures of expectations placed on patients, including rules on how to behave in an environment. This also influenced the staff's perception of the behaviour as challenging. For instance, Emma talked about socially constructed rules in the dining room and the staff's beliefs and behaviours being informed by these constructs.

> *"If they're sat in the dining room ... those social constructs of this is how you behave in a certain place really has an impact on someone, and also how we as staff believe that they should behave in that situation" (Emma)*

Mary discussed her experiences of staff's dismissive attitudes towards people with behaviours that challenge which limited their ability to analyse and hypothesise about a behaviour. This resulted in staff wanting the behaviour to stop rather than working to de-escalate the situation. Similar to Jenny, Mary positioned herself against this naming it a "*staff attitude thing*". Mary also talked about having to "*pursue*", which suggested it is not always easy to understand the behaviour and that it takes an active effort to analyse. This may have impacted the helping behaviours in turn displayed by the staff. Furthermore, as Mary seemingly wants to understand, which is evidenced by her pursuit, she is opposed to the limited staff attitudes displayed.

> *"It's a staff attitude thing ... there's definitely staff that don't want to pursue and don't want to see maybe why that behaviour is happening it's just a 'stop it'" (Mary).*

1.3 Making Sense Through Analysis

HCAs had an active role in the analysis element of PBS; their observations and hypotheses contributed to the team's understanding of behaviour. This process of analysis framed their understanding of behaviour. For instance, Mary said there was always a "*reason*" for behaviour, and it was her role to explore factors contributing to behaviour through her observations. She continued to say she considers biopsychosocial factors, including learnt behaviour and physical and mental influences on behaviour. This analysis of behaviour continued despite the challenges HCAs experienced when working with people with behaviours that challenge.

> *"That behaviour is there for a reason ... we have to sort of try and unpick and that's by doing ... a lot of watching, a lot of listening, a lot of talking to other people ... behaviour is there for a reason, whether that's physical ... mental ... it's you know [pause] learnt" (Mary)*

Mary showed that she aligned herself with the PBS framework through the language and phrases she used such as "*the behaviour is there for a reason*" and "*unpick*" which demonstrates the process of analysis.

Yelsel acknowledged the difficulties associated with patients' behaviour but she postulated the reasons for them, including the need for safety and attachment. She admitted she was unsure of her hypothesis and noted the differences in participants' presentations and their backgrounds, leading to differing hypotheses about the maintaining factors of behaviour. The analysis of behaviour involved HCAs formulating and testing hypotheses as they were tentative and not fixed:

> *"It was in his PBS plan where we had to give him pressure but he used to scream the night ...I don't know what it does? It must make them feel, I don't know, safe ... [pause] they are all a little bit different so I suppose it depends on the behaviour" (Yelsel)*

Emma talked about the 'assumptions' staff make about their interventions being conclusive evidence of their analysis; "*we just assuming what we do helps because it maybe de-escalates a situation but that maybe doesn't help their mental health" (Emma).* However, she perceived behaviours as complex formulations and an intervention reducing behaviour did not ensure that they met the underlying function of a behaviour. She gave an example from her experience, that illustrated the use of restrictive interventions to reduce behaviour but it did not meet the person's sensory needs and instead was a form of negative reinforcement of behaviour:

"if someone starts headbutting a wall you know we might go in and restrain them, they might go, okay I don't like being restrained so I'll stop … I need to do this but give me a cushion, because there might be a sensory need there" (Emma)

2. Using PBS as a Health Care Assistant

Healthcare assistants had a large role in the implementation of PBS in the ward environment. This theme included subthemes that discussed HCA's experiences of following patients' PBS plans and the influence on their practice, HCA's involvement in creating PBS plans, and the difficulties and successes of working with people whose behaviours may challenge.

2.1 The Involvement of HCAs in the Development and Implementation of PBS Plans

There was a variation in the extent to which HCAs were involved in creating PBS plans, with some feeling more involved in this process and others feeling like they were an underused resource. Yelsel explained the importance of involving HCAs, as they work directly with patients on the ward and therefore had the most information to contribute to a PBS. She talked about "*those sat in the offices*" when describing people who create the PBS plans, which implies that those people are less involved and understand less than the HCAs that "*work on the ground*". HCAs have more information than those who create plans and their observations are what comprised a PBS plan. She uses phrases like "*we know obviously more*" and "*see what actually happens with the patients*" to denote that it is clear to her that HCAs hold the most information on patients and they must have a key role in creating plans.

Other HCAs were content with the amount they were involved in PBS plans; "*there's obviously an opportunity" (Jenny).* She reflects that HCAs are important in the process of creating PBS plans and are automatically involved. Jenny described a consultation-type role she has had with a PBS coach where she is asked for her opinion and it is valued. She also believed she could question the content of a PBS plan and provide additional information.

> *"I have updated the plan, have a read, what do you think? And then there's obviously an opportunity to go up to them and say actually I'm not quite sure what you mean by that or can we add this?" (Jenny)*

Emma spoke about the barriers to HCA involvement due to the nature of their responsibilities; *"Because of how busy we can be not everybody gets that opportunity"*. Emma felt that the difference in inclusion levels negatively impacted the PBS plan as it was contributed to by people with similar opinions; *"will take the PBS in a certain different way"*. There was an unheard population of HCAs who were not contributing their views, the consequence being that some HCAs implemented PBS plans that they had not created and may not have agreed with: *"a larger portion of people, don't agree or sometimes aren't on shift or don't have time" (Emma)*.

HCAs generally agreed that PBS plans did not dictate how HCAs work, but they influenced their approach. *"Sometimes that's all it can be good for is just a bit of guidance, they don't always have to follow everything on that plan because not everything works most of the time*" *(Emma)*. Emma's description illustrates that PBS is only part of the overall care plan for the patient and is not a 'miracle' that will work all of the time, it needs to be used alongside other skills and interventions.

Similarly, Mary talked about having to adapt the PBS plan for the variety of situations she was in with a patient. *"I wouldn't read a PBS and go "right okay, that that's what I'm doing" ... You have to you have to get to know that person... people are different with different people with different environments different things" (Mary).* Mary perhaps insinuated that an over-reliance on the PBS plan reduces the person-centredness of her healthcare work. And, to show the true importance of a PBS plan, they "*have to*" be adapted to the environment, staff team, and individual patient differences. Through this quotation, Mary also highlighted the value of authenticity and personal connection to those who use the service.

Similarly, Dave described an over-reliance on PBS plans that caused interactions to *"seem a bit like clinical and not very like person-centred".* Dave continues, *"although the PBS is entirely person-centred".* Dave implies that being over-prescriptive opposes the key aim of PBS and negatively impacts the therapeutic relationship with the patient; it becomes rigid and less genuine.

2.2 PBS Intertwined in HCA Work

HCAs discussed how PBS was intertwined with their role. There was a divide between new and more experienced staff working in intellectual disability services, with new staff perceiving PBS as a more recently developed approach that has helped to shape their practice, and more experienced staff seeing PBS as a framework that has long underpinned their practice.

> *"it's not just about me using my initiative… written up by doctors and psychiatrists that is like the gold standard of this will work so do this. So it's given me a lot of confidence because you're not just winging it… to sort of back you up or guide you" (Dave)*

Dave spoke highly about the value of having PBS plans to guide his approach; he felt more confident and reassured by the presence of a plan. He compared his "*initiative*" to the PBS plan being a "*gold standard*", suggesting that he may perceive PBS to be the highest level of care for patients with behaviours that challenge. Furthermore, PBS unites the team's views and helps the staff to feel supported in the care they are providing.

PBS became ingrained in the way HCAs worked, for instance, Roger shared *"that probably was working with the PBS but I probably wasn't conscious … that I was doing it in a positive behavioural support way it was just I have knowledge about this person now".* Roger had picked up the key information to develop his understanding of the person and integrate this into his work and become more proactive.

Jenny developed a "*gut feeling*" from her experiences working with people who displayed behaviours that challenge. She instinctively picked up on nuanced changes in a person's communication to predict a change in their behaviour:

> *"there was something in his presentation that wasn't right … how he communicated … on the Monday and by the Wednesday he was assaulting staff and ended up in seclusion… triggers where already there it's just picking up and acting on them" (Jenny)*

Jenny suggested that she was better at foreseeing this than others and that the team was inefficient in acting upon the information she shared. She later explained that not everyone had such a "*gut instinct*" and that it was something she acquired through her experiences working with people with behaviours that challenge.

Mary worked as a HCA with people with intellectual disabilities for 35 years. She reflected *"We've always put something like that in place",* she has "*always*" worked in-line with the PBS approach and its values. PBS offers a framework, similar to her instincts, that is promoted within the service and provides safety for staff to know they are following a standard. She also acknowledged that there had been some change in what PBS represented over time:

> *"I think it's just it's become a thing it's become you know "this is what we have to do, this helps" … I think it's promoted … the actual content … pretty much the same, it's probably come on a bit" (Mary)*

2.3 Successes and Positive Challenges

The successes of using PBS were explored, including improvements for patients and the benefits for staff. The successes of PBS were often defined by the reductions in the frequency or severity of behaviours that challenge and the reductions in restrictive interventions. Dave described the change for one person as *"Now he is a totally different man… his life has literally taken a complete turn".* The use of PBS resulted in the patient being seen in a different light despite him being the same person and illustrates that this is a significant change for the patient.

Dave also spoke about the turning point in the PBS intervention related to the patient-HCA relationship that was the catalyst for the change. "*eventually they'll kind of they'll just click and you'll start, both you and the patient, just getting each other more and you'll just make so much progress with the relationship" (Dave).*

For Jenny, the presence of a PBS plan increased her confidence to work in her role where she supported patients independently. This also suggested that safety is typically provided by working with teams, and the PBS plan somewhat emulates this. Furthermore, Jenny demonstrated that the PBS allows staff to feel safe and contained. Jenny's laugh in this instance may suggest that she is aware of the potential consequences if a PBS plan is not formulated when appropriate or required.

"I'm grateful for it actually being in place [laughs] because a lot of the time I do work independent ... without support staff so I need to have that confidence to be able to pick up them clues of someone getting fed up or getting agitated and de-escalate…" (Jenny)

Mary paused and reframed the use of the word "challenge" when asked if there were any challenges in her experience. She opposes herself to the negative connotation that is associated with challenge and instead discussed the positive components of challenge in the job. The challenge was something she enjoyed, and she was able to see more change when there was more challenge.

> *"The job itself [pause] it challenges in me in the sense that I like doing this I like I like a challenge, I'm one of the people I think that works more on adrenaline, I like the more challenging person because I find it more rewarding to see that behaviour managed differently" (Mary)*

2.4 The Challenges of working with BTC and Risk

The physical and mental challenges HCAs experienced working with people with behaviours that challenge were frequently highlighted. For instance, "*If you're on there all week [sighs] your feet are killing you by the end of the week and it's mentally draining as well definitely" (Yelsel).* Through the use of emotive language and non-verbal cues, such as sighing, Yelsel emphasised the physical, cognitive and psychologically demanding nature of working several shifts.

The dedication of HCAs was also highlighted by Emma, who shared the extent of time she has spent with patients. *"We spend a lot of our lives … three or four days a week for twelve hours a day … Christmases and birthdays" (Emma)*. Through the use of numbers and significant dates, Emma evidences how invested she is in her work.

Emma discussed the transference of stress experienced by patients to the HCAs after spending prolonged periods at work. *"you take on a lot of their stresses as well so sometimes you just need a vent … you do always have the option of supervision with people like [psychologist] and management … I think that can be helpful, sometimes that doesn't work at all, sometimes you get to a point where you're so drained that you need to take time for yourself" (Emma).*

Emma reflected that "*venting*" to her colleagues was more useful than formal supervision, perhaps because they experienced similar pressures to her. Furthermore, she distances the psychologist and management from her experiences, again showing how there may be a perception that they do not share the same experiences as HCAs and therefore are not the most helpful to receive supervision from. She talked about how when the stress accumulated, not even supervision was supportive and she has had to take time away from work to reduce her burnout.

Although the use of PBS plans was praised, there was an acknowledgement of the barriers to their implementation. For example, Emma described the risk as a priority and at the forefront of her mind when there was a behaviour of concern:

> *"If that person is punching someone you have to just kind of deal with that behaviour rather than looking at or observing the behaviour… keep that person safe and the other people safe … you have to kind of retrospectively look at it" (Emma)*

She used emotionally charged language such as "*punching*" to show the urgency of the risk. There was no time to observe and hypothesize and this negatively impacted her ability to think analytically about behaviour. The safety of a patient was paramount, and analysis took place retrospectively after the event.

When restrictive interventions had been used, Dave found it difficult to use a PBS approach and implement a PBS plan, *"Challenging because you're trying to get through to someone just like through a door or a window".* The physical environment was an obstacle to Dave, he felt like he could not use the PBS techniques to support the patient. He talked about *"rely on just your communication and you're sort of interpersonal skills"*, this showed that the usefulness of the skills reduced. Furthermore, when the skills did not help to engage with the patient in seclusion he used language such as "*stuck*" and "*lost*" to reflect his frustration with using PBS in seclusion.

3. Relationships

This theme explores the HCA's experiences within different relationships. The subthemes include HCA's relationship and position within the wider MDT and how this influenced the PBS approach. Furthermore, HCA recalled building therapeutic relationships and observing those relationships break down. Moreover, the barriers to the inclusion of patients in the PBS approach and suggestions on how to improve this, through the relationships HCAs have with patients, were also raised.

3.1 A Consistent, Cohesive and Persistent MDT Approach

The team working cohesively and together was valued by the HCAs. Emma suggested that PBS enabled staff to be consistent in their approach, as they were following the same care plans and had a shared understanding. She indicated the importance of a consistent approach from the whole MDT when supporting people with intellectual disabilities and autism to reduce confusion and prevent distress.

> *"If you've got a cohesive staff team that are all on the same page … then you've got consistency …for our patients are key … with autism, patients with a learning disability, if you've got somebody coming in and saying one thing and another person saying another it's so confusing for us as staff let alone a patient" (Emma)*

The process of supporting people with behaviours that challenge was described as slow-moving and required HCAs to persevere and be persistent in their approach, *"Slowly with PBS's, with support from staff, with determination" (Mary).* This illustrates that PBS requires maintained effort.

Mary evidenced the success of PBS by talking about the reduction in the severity of behaviours and patients moving back to the community. *"that's the reward seeing people going from here and back into the community".* Furthermore, Mary compared her mindset to others who are more pessimistic about the likelihood of change, "*people go "oh their behaviour is ooooh they'll never be able to do that" yeah we've seen that and we've done that as a team, I think we are very good at it".* Here, Mary reinforces the importance of a cohesive and consistent staff team concerning successfully developing and implementing PBS on the ward.

A frustration HCAs experienced was being part of the multidisciplinary team, as each member had a different perception and approach: "*every professional will have a different approach and there might be conflict there"*. Jenny talked about surmounting barriers to "*work for the greater good".* This again illustrates the importance of cohesion in delivering effective and patient-led care. PBS is a key facilitator of team cohesion as it considers the variety of opinions and observations from each member of the MDT. Furthermore, it offers a framework from which everyone can work together.

> *"I think this is where the PBS comes … everyone agrees with that approach and it's like a set of guidelines, rules and you know obviously a plan … so if we stick to that everything's fine" (Jenny)*

3.2 The Therapeutic Relationship

The relationship between HCAs and patients was imperative, especially due to the extent of the time they spent together. The PBS value of person-centred care was noted to be essential in building close therapeutic alliances with patients.

It has already been noted that person-centred care is important for Dave in his work. Here he shared that gaining in-depth knowledge about the patient's history and preferences from the PBS plan allows him to adapt his approach promptly and develop the therapeutic relationship sooner than without a PBS plan:

> *"a bit more of a knowledge on someone to know maybe the best way to sort of engage with them ... it probably helps you develop a relationship quicker because you know more about them you've got likes and dislikes ... tailor your approach… to be a bit more person-centred with them" (Dave)*

Once there was a therapeutic relationship established, Dave believed patients were able to feel safe as they were confident in the abilities of HCAs. Furthermore, the sharing of information about patients, provided by a PBS plan, gave patients reassurance in the HCAs' support. Dave continues to highlight the importance of warm interpersonal skills when building relationships with patients:

> *"Build a more therapeutic relationship with them and then they feel safer or they feel more confident in your skills ... I think it probably reassures them to know "oh I know if I do this I'll be safe because he [Dave] knows this about me" (Dave)*

In Jenny's experience, the use of restrictive interventions and restraint negatively impacted the therapeutic relationships between staff and patients. When there is an increase in risk and the alarms are raised on the ward Jenny still thinks about the therapeutic relationship first. "*I don't want to be that initial team that goes rushing in to restrain because that breaks down that relationship [pause] you know the trust is gone and you can't get that back because from their point of view it's well you held me down you're not my friend"*. Through initial consideration and hesitancy, Jenny seemingly attempts to strike a balance between developing and maintaining trust in her relationships with patients, whilst simultaneously managing risk appropriately.

Despite the relationship breaking down, Jenny experienced, with persistence, that the therapeutic relationship could be rebuilt, *"It can be hard but that can come down to us being confident ... empathy and compassion I think, understanding why that person's got upset".* Here, empathy and compassion were crucial, particularly in communicating HCAs' understanding of the justifications for a person's distress and normalising their behavioural expressions; *"it's not wrong to get upset, you know you're no different to the rest of us as human beings ...they shouldn't be penalised".* The use of a person-centred and positive approach after a restrictive intervention not only illustrates Jenny's understanding of how restrictive interventions can be seen as a punishment for behaviours that challenge, but also that the role of the staff team is to ultimately support the patient in their care.

3.3 Patients Should be Involved More but There are Barriers

Other themes have emphasised the cohesion of teams and the inclusion of HCAs within PBS plans for optimal implementation of the framework to support patients. Continuing from this, all of the participants believed patients should also be involved in the creation and evaluation of their PBS plans. However, the barriers to such involvement were outlined, including the nature and severity of the patient's distress and their cognitive and communication abilities, *"I just don't think it's as much as it should be ... it's very difficult because of the type patients we have in, patients coming in, in crisis situations, learning disabilities and the barriers of that and the barriers of autism and communication skills" (Emma).*

Emma spoke about her role in facilitating conversations with patients to hear their views on how HCAs should support them, focusing on when they displayed behaviours that challenge. "*you should be able to sit down with someone and say when this happens what would you like us to do? How can we help you?" (Emma).* This debriefing is seen as key to maintaining the PBS plan as person-centred and also ensuring it is preventative. The questions Emma used as an example reflect the position that it is the staff that make changes rather than the patients to reduce the frequency of behaviours that challenge.

Jenny suggested adaptations that can be made to involve patients and overcome the barriers of communication and distress. As part of her role, she supported patients with activities such as arts and crafts and noted that patients were more relaxed and likely to talk openly about their experiences. *"While they are focussing on ... art and crafts, they are quite open to discussion because they're distracted ... they're comfortable and relaxed they'll discuss things that have upset them in the past"*. This approach opposes the 'traditional' formal methods of getting participants' views that often created more distress; "*they're not open to the doctors ... they don't relax enough to start being open".* This reinforces the participant's views that they have a more appropriate skill set to work with patients and can be a conduit to involving patients in their care. Jenny then shared the information with the wider MDT and this became part of the PBS plans.

Furthermore, Roger explained that patient involvement may increase if PBS plans were explained to patients as supportive plans to increase their quality of life and support them to transition to the community. Perhaps this suggests that PBS is not always well explained to patients and the purpose is not well understood. Language such as "*sustainable*" reflect the aim of staff to reduce patient admissions and support patients to live in the community. Moreover, PBS is a tool for patients to share information about themselves so that staff teams can use it to provide more appropriate support.

> *"I think if they can see it's all about their best interests and a way of getting them off the inpatient unit and back into the community in a sustainable way where they will have staff that understands their likes and dislikes and what their trigger points are erm yeah it's got to be a good thing" (Roger)*

Discussion

Overall Findings

The research explored the experiences of health care assistants supporting people with intellectual disabilities who display behaviours that challenge in an inpatient service that utilised a PBS framework. Furthermore, to explore their attitudes, perceptions and beliefs working with people with intellectual disabilities and behaviours that challenge within the inpatient service that used the PBS framework. Three superordinate themes were constructed from the participants' interviews and ten subordinate themes. These encompassed understanding of behaviours that challenge, the use of PBS as a HCA and relationships. The themes overlap with the key components of the PBS framework, including the values, theory and evidence base, and process outlined by Gore et al. (2013).

HCAs demonstrated a holistic understanding of people with behaviours that challenge which included the consideration of biopsychosocial factors such as the inpatient environment and trauma. This is consistent with the conceptual model outlined by Hastings et al. (2013) and illustrates that HCAs have a depth of knowledge about the vulnerability factors contributing to the behaviours that challenge being displayed. Furthermore, they associated a change in their perspectives with their increased use of PBS. The attributions HCAs made were evident in their descriptions of their understanding of behaviours that challenge and the implementation of PBS in their work (Weiner, 1980). For some, their perspective developed from attributing behaviours that challenge as internal to the person with intellectual disabilities to a more external locus of control outside of the person that maintained their distress. They sustained this understanding despite the severity or type of the behaviour they observed. This opposes literature that suggested the attributing external locus of control was only applied to self-injury (Stanley & Standen, 2000). The change in attributions made by

HCAs is similar to research on PBS training facilitating care staff having more positive attributions towards behaviours that challenge (Wills, Shephard & Baker, 2013).

HCAs understood the behaviours that challenge displayed by people with intellectual disabilities through the use of functional behavioural analysis, an important method in PBS (Sugai et al., 2000). This included using their observations and direct experiences with patients to formulate hypotheses of behaviour from which PBS plans were created. HCAs were tentative in their hypotheses and acknowledged the impact of societal discourses on people with intellectual disabilities and social constructs that impacted their perception of what constitutes a behaviour as challenging, this is similar to the maintenance factors outlined by Hastings et al. (2013). Participants spoke about being flexible and adaptable in their approach, and PBS plans were used as guidance as they prioritised the person-centredness of their approach. They went further to suggest that rigidly sticking to a PBS plan reduced their autonomy and the authenticity of interactions with patients. Therefore, HCAs were important in upholding the person-centred values of PBS and being needs-driven rather than service-driven (Carr et al., 2002).

HCAs are categorised as key stakeholders in the process of data-driven functional assessments and implementing multi-component interventions outlined in the PBS framework (Carr et al., 2002). Participants spoke highly of their extensive knowledge of patients due to the intensity and magnitude of direct interactions; they were important collaborators in the process of PBS. Participants had experience with assessment and implementation. However, it was expressed by some HCA that they were underused resources and that there were barriers to their involvement which needed to be overcome. This included barriers associated with the characteristics of their role, such as shift working and constant engagement with patients, but also external pressures such as staff shortages and COVID-19 (Deakin, 2022).

The risk associated with behaviours that challenge was highlighted as an important aspect that HCAs had to be aware of. The risk was seen as a priority to ensure patient and staff safety and often disrupted the process of functional analysis. Research suggests that PBS plans reduce the use of restrictive interventions, including restraint and seclusion, due to the preventative nature of the approach (Clark, Shurmer, Kowara & Nnatu, 2017). The successes of PBS described by HCA included the reduction of restrictive intervention and the transition of patients to the community. Furthermore, PBS became ingrained in HCA’s work and their “gut instincts” resembled the proactive nature of PBS and HCAs described detecting subtle changes in a person’s presentation to prevent behaviours from escalating (Gore et al., 2013). The difficulties of implementing PBS alongside a restrictive intervention such as seclusion were explored, including the disruption of the therapeutic relationship and the challenges HCAs faced when adapting to the restrictive environment.

The importance of therapeutic relationships between HCAs and people who display behaviours that challenge was emphasised. Person-centred care is facilitated by therapeutic relationships, which are developed through open and honest communication, empathy, compassion, and information sharing (Doherty & Thompson 2014). In the experience of the participants, PBS allowed the relationship to develop quicker as HCAs had extensive knowledge of the person’s background and could adapt their style to the person’s preferences. Similarly, Jaques, Lewis, O'Reilly, Wiese, and Wilson (2018) discussed the importance of the relational skills of nurses supporting people with intellectual disabilities, which assist in the delivery of person-centred care. They emphasised the significance of getting to know the person, even though this may be complex and take time, and staff need to be adaptable and resilient. Participants reported the use of restrictive interventions such as restraint, which broke down the therapeutic relationship as patients did not feel safe and could not trust the staff. HCAs used empathy and compassion to rebuild relationships after the use of restrictive interventions. Chieze, Hurst, Kaiser, and Sentissi (2019) suggested that the negative emotions associated with restrictive interventions, such as loneliness and helplessness, may be reduced through the development of a secure therapeutic relationship with staff.

PBS requires cooperative work from members of the MDT and effective teamwork (PBS Academy, 2015). The relationships and dynamics within the MDT were discussed by participants. From their experiences, a consistent and cohesive approach was the most effective way to facilitate the implementation of PBS interventions. This created a predictable and safe environment for patients and facilitated the development of trusting HCA-patient relationships. It is important to acknowledge the risk associated with burnout for HCAs. Wallang and Ellis (2017) highlight the impact of working directly with a patient’s distress and the importance of developing HCA’s resilience through support, using supervision and reflective practice. Participants reflected on the value of talking with colleagues who experience the same stressors as well as the use of supervision.

Implications for Clinical Practice

Stakeholder participation is a central value of the PBS framework. Stakeholders who support the individual and the individual themselves should be consulted and involved in the PBS process (Gore et al., 2013). Participants' experience and involvement in creating PBS plans varied, as some felt they were consulted and others felt left out of the process. Participants suggested that their knowledge and experience working “on the ground” with patients is invaluable and more detailed than those who typically create PBS plans. One participant suggested that if only certain members of the team are included, then the PBS is not reflective of everyone’s perspectives. Suggestions for improvements included a longer period to gather information from HCAs so that it covered people on different shift patterns and more accessible methods of data collection, such as email, so they could contribute outside of work hours. Another way to improve inclusion may be to have HCAs take a leadership role in collecting and collating PBS plans. This type of transformational leadership that encourages problem-solving and responsibility in the care of patients is associated with job satisfaction and psychological wellbeing (Munir, Nielsen, Garde, Albertsen & Carneiro, 2012). This would need to be supported by appropriate training and supervision.

Overall, participants felt there were several barriers to patient inclusion in the PBS process, including its accessibility for people with intellectual disabilities and people experiencing high levels of distress. Participants were united in the belief that the service should do more to facilitate patient involvement, and they had begun to do this through more informal methods such as having conversations about triggers to behaviour when patients felt relaxed and comfortable. This would increase the levels of involvement of people with intellectual disabilities in their care and increase levels of self-determination, which is associated with experiencing a higher quality of life (Shogren, Wehmeyer, Reese & O'Hara, 2006). One way to increase the accessibility of the information in PBS plans for people with intellectual disabilities is the inclusion of easy-read text, symbols, or pictures (Sutherland & Isherwood, 2016).

Implications for Future Research

This research highlighted the implications of using restrictive interventions such as restraint and seclusion on patient wellbeing, therapeutic relationships, and implementation of PBS. Nationally, there is a drive to reduce the use of restrictive interventions within inpatient services, particularly for people with intellectual disabilities (Department of Health, 2014). Future research investigating the use of PBS to support the reduction of restrictive interventions within inpatient services would be worthwhile. Furthermore, there is a focus on reducing the number of people with intellectual disabilities in inpatient services, particularly when they could be more appropriately supported in the community (NHS England, 2019). Future research could explore the use of PBS to support people with intellectual disabilities in transitions from inpatient to community services.

Strengths and Limitations

The participants included in the research were healthcare assistants working in one inpatient service supporting people with intellectual disabilities in the North East of England. Therefore, one strength is the homogeneity within the sample that provides insight into the specific experience of working within a PBS framework as a HCA (Smith & Nizza, 2021). The differences between participants were instead related to the length of time working with people with intellectual disabilities, four years to thirty-five years, and a range in the length of time they worked in this inpatient service, from two years to sixteen years. However, an area that could be improved upon in future research could be a greater range of cultural diversity in participants, particularly as one factor influencing the perceptions of care staff supporting people with behaviours that challenge is culture (Hastings et al., 2013). Furthermore, it was suggested by one participant that not including a range of HCAs within the service influences the type of PBS plan created (Emma 2.1.3). Holding this in mind, it is important to acknowledge that the purposive sampling may have inadvertently excluded HCAs that work nights and those less confident in sharing their views.

Moreover, as the sample of participants was recruited from one inpatient service, the findings are not generalisable to other inpatient services that provide support for people with intellectual disabilities and behaviours that challenge.

Conclusion

This study highlighted the experiences of health care assistants working within a PBS-informed inpatient service to support people with intellectual disabilities who display behaviours that challenge. It reflected the perceptions HCA had of behaviours that challenge, how they flexibly implemented PBS in their role, and the importance of relationships within the MDT and with patients. Suggestions were made for clinical implementations and future research.

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Part Three: Appendices

Appendix A: Reflective Statement

As I sit here to write my reflective statement I am surrounded by notes from my reflective journal trying to piece together the ups and downs of the whole research process over the past three years. I will attempt to coherently reflect on the impact this research has had on me and the impact I had on it. This is a big task, as was conducting a research study and writing a doctoral thesis but I am truly grateful to have had this experience and opportunity.

Developing the research

As we were encouraged to begin thinking about the development of a research idea in the first year of the course, I recall feeling overwhelmed with uncertainty of what to do. Unlike some of my peers, I had not developed a specific interest and was open to most areas in Clinical Psychology. It was on my first placement, in a Community Intellectual Disability Team, where I first came across the idea of PBS and how it had been used to support people with intellectual disabilities in the community. It was my supervisor who suggested to pursue research in this area and it was an area familiar to me as one of my volunteering experiences prior to the course was supporting a social group for people with intellectual disabilities.

There was something about the values of PBS that spoke to me that were in line with my own. The focus on improving quality of life and increasing positive outcomes for people with intellectual disabilities was akin to my own interests in positive psychology and strengths-based approaches. I was interested in the idea that the caregivers around a person could change their approaches and behaviour to better support them rather than a focus on what the individual had to change. I think that was also influenced by being brought up by a mum who is a health care assistant. Over the years she has worked to care for people living with dementia and more recently people with intellectual disabilities in the community. I have always admired her self-less approach to caring for others and her passion to improve the lives of people she works to support.

Empirical

A large catalyst to developing the idea that went on to become my empirical study was meeting with my field supervisor. His enthusiasm and interest in PBS helped me explore the possibilities of the research study. This also gave me the opportunity to consider conducting research within the inpatient service supporting people with intellectual disabilities. I was able to meet with some of the healthcare assistants to ask for their perspectives on the research and for them to be involved in the development of research documents and interview schedule. It was reassuring to hear the research would be relevant to their work and something of value. From the research I was reading on the PBS approach and healthcare staff, the voice of health care assistants in particular had not been heard. There were no links made between the aspirations of PBS as an approach and how it is used on the ground level, the people who work day in and day out with people with intellectual disabilities who display behaviours that challenge. Therefore, using IPA felt the most appropriate due to its phenomenological and idiopathic underpinnings and the positioning of the participants as “experiential experts” (Smith & Nizza, 2021, p. 6).

The process of ethics application and approval was long and arduous. The stringent nature of NHS staff ethics was of course understandable but something that took a long time to complete and it felt that each time I completed one stage there was another hurdle to jump over. When I finally gained ethical approval in February I felt relief but also a sense of urgency to begin data collection with the first deadline quickly approaching. I had to step back many times from comparing my progress in research to my peers who seemed to be light years ahead of me.

Data collection was the part I was most looking forward to starting. I had high expectations that this part of the research would be “smooth sailing” and something that would not take too long to do. Upon reflection, that was incredibly naïve of me. I had not considered the sheer number of obstacles and pressures that were outside of everyone’s control. Whilst the country had begun to “move on” from the pandemic, the NHS was continuing to struggle with this crisis. HCAs were up against Covid-19 restrictions, staff sickness and staff shortages whilst also experiencing the everyday challenges of high demands, long shifts and working with high levels of risk. Therefore, it was understandable that it took longer than anticipated to collect the data. I had to be more flexible in my approach, I came to the unit on weekends and evenings to fit around their shift patterns. Additionally, I had to get used to going to the unit to conduct the interview but knowing that there was a high chance the interview would need to be rescheduled due to challenges they were facing on the shift. We also conducted one interview virtually to overcome the Covid-19 restrictions. I was so grateful for all the staff that showed interest in my research and especially to those who gave up their time to share their experiences. And although it was disheartening to hear HCA experiences of not always being heard it solidified the importance of the research in sharing their experiences and expert knowledge in this area.

Whilst collecting data I begun transcribing and analysing each interview individually. The amount of qualitative data I had collected was overwhelming and I found myself taking a very methodical approach to analysis to keep the process moving forward. I printed out each interview, I cut out and moved around experiential statements to cluster and create personal experiential themes and eventually group experiential themes. I had lots of tables which allowed me to trace each cluster (and eventually each theme) to an exact quote in the transcript. When I began cross-analysis, I knew I needed to construct themes that reflected the similarities and differenced in their experiences but I was stuck with wanting to capture every element of each participants interview and not leave out anything important. This is where supervision was particularly useful to share those anxieties and also give myself permission to not include everything. I was able to capture the main themes and include other important quotations within the appendices.

Writing up the empirical paper was something that took place in stages. For a while I had the introduction and methods written waiting for the results to accompany them. Taking the themes from a collection of clusters of experiential statements to a written narrative supported by quotations was demanding. I often questioned if I was “doing it right” and struggled with being confident in my abilities but this is where my methodical approach to analysis came in helpful. Writing the discussion was also tricky. Although it felt more straightforward as it was more structured, I felt pressure to write something that summarises the whole project, makes link to literature in the field and make educated recommendations.

Systematic Literature Review (SLR)

Alongside the process of ethical application, I started to really knuckle down with writing the SLR. I found it easier to tackle the SLR in one full sweep, blocking out weeks of study time to spend in the library to take on the mountain of work. The topic of the SLR was born from the literature I had been reading for the empirical paper, looking at the gaps. I learned quickly that the SLR was, by nature, a cyclical process. Generating search terms, searching and reviewing the literature, then adjusting the search terms and starting again. The topic area started broad, people with intellectual disabilities who display behaviours that challenge and with each loop round the circle it became more and more focussed. There was a point where the SLR could have gone one of two ways; looking at experiences of those supporting people with intellectual disabilities and behaviours that challenge or the outcomes of using PBS to support people with intellectual disabilities and behaviours that challenge.

The first area was closely related to the empirical study and may have resulted in too much of an overlap and the second area had more literature that could be included in the review. From this, the search became more refined and eventually I got to the final pool of papers.

Although the process of the SLR was more methodical and structured, I struggled with doubt at every stage. I particularly wrestled with the synthesis stage and whilst choosing narrative synthesis was straight forward, as it was the most appropriate for the mixture of methodology in the literature pool, this was a completely new and unfamiliar approach. One thing I found that helped with the analysis was the mapping out of themes and the narrative associated with that. Linking each theme with qualitative and quantitative results from the papers ensured it was grounded in the data.

Summary

In summary, despite the challenges it is important to highlight the positives and rewards of this process. I learned to normalise the feelings of uncertainty and second-guessing myself, this showed that I had so much invested in the thesis and drive to complete it. Supervision was such an important part of the research, the reassurance Nick provided kept me anchored and focussed on the next steps. The feedback from Nick and my peers who read through my many drafts and segments of work was invaluable, even though I sometimes doubted the positive feedback as I anticipated critique. I also learned a lot about empirical research and systematic literature reviews. I began to think more critically about the literature I was reading, value the role of research in amplifying the voices of groups and become more self-reflective. The skills I learned will accompany me into my career and hopefully I will put them to use in the future.

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Appendix B: Epistemological Statement

Epistemological assumptions are “associated with the nature of knowledge and the methods through which that knowledge can be acquired” (Bahari, 2010, p. 22). Al-Ababneh (2020) discussed the links between the epistemological assumptions of a researcher and the research process, highlighting how it informs the research methodology and the methods of data collection. The epistemological statement outlines the researcher's assumptions and how they informed the research process.

A critical realist position was taken by the researcher. This assumes the existence of an objective world and also that knowledge is subjective and changed by social constructions (Vincent & O'Mahoney, 2018). A qualitative methodology was used in the research as it is concerned with people’s experiences and the meanings they attribute to them rather than the cause-effect relationship between variables (Willig, 2013). Semi-structured interviews were used to allow for rich data to be collected on participants' experiences of PBS and supporting people with behaviours that challenge. The qualitative approach meant that perceptions, attitudes, and attributions could be explored at an individual level. The previous literature in this area has used quantitative techniques. For example, MacDonald and McGill (2013) measured the change in participants' competency in PBS after training. However, this does not give insight into their understanding of PBS and their experiences of implementing the framework.

Interpretative Phenomenological Analysis (IPA) is a qualitative method used to explore experiences of a particular phenomenon and is underpinned by theories of phenomenology, hermeneutics, and idiography (Smith & Nizza, 2021). IPA relates to the assumptions of critical realism as it proposes that while the experiences of participants are subjective, they are experiencing and perceiving the same objective reality (Jeong & Othman, 2016).

The use of supervision and reflection during the research process was important, particularly due to the double hermeneutic process in IPA, where the researcher interpreted the participants' sense-making of what they experienced (Smith & Osborne, 2003). Self-reflexivity included keeping a research diary and being aware of opinions and assumptions about the topic area. Furthermore, acknowledging the preconceptions prior to interviewing participants.

One way the researcher ensured validity was by having two independent auditors, the research supervisor and a peer, audit the analysis process at various stages, from establishing themes to write-up (Shinebourne, 2011). In sharing the themes generated from the research, grounded in the participants' quotations, the intention is to share the researcher's interpretation of the participant's lived experiences and to amplify their stories (Alase, 2017). Due to the idiographic nature of IPA and the homogeneity of the sample, the researcher is cautious to not generalise the conclusions and recommendations.

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Appendix C: Author Guidelines for the Journal of Applied Research in Intellectual Disabilities

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, new submissions should be made via the Research Exchange submission portal: **https://wiley.atyponrex.com/journal/JAR**. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging in to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our **FAQs** or contact **submissionhelp@wiley.com**.

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This journal participates in the Wiley Special Education publishing network and the **Wiley Developmental Science Publishing Network**. This exciting collaboration amongst our Special Education and Developmental journals simplifies and speeds up the publication process, helping authors find the right home for their research. At the Editors' judgement, suitable papers not accepted by one journal may be recommended for referral to another journal(s) in the network. Authors decide whether to accept the referral, with the option to transfer their paper with or without revisions. Once the referral is accepted, submission happens automatically, along with any previous reviewer reports, thereby relieving pressure on the peer review process. While a transfer does not guarantee acceptance, it is more likely to lead to a successful outcome for authors by helping them to find a route to publication quickly and easily.

2. AIMS AND SCOPE

JARID is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

In order for a paper to be considered for publication, it must be about people with intellectual disabilities. Manuscripts which focus upon autism will be considered only when the focus is also upon intellectual disabilities. Papers which focus upon autism and exclude people with intellectual disabilities will not be considered.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision.

Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Original Articles, including Clinical Trials (see guidance within section 5), ***Review Articles*** and ***Brief Reports*** are accepted by the Journal. ***Theoretical Papers*** are also considered, provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Authors who are submitting original articles where qualitative methods have been used must ensure that their choice of method is well justified and issues relating to methodological rigor are effectively addressed.

Articles and ***Theoretical Papers*** should not exceed 6000 words;

Review Articles should not exceed 7000 words;

Brief Reports should not exceed 2000 words.

All word limits are inclusive of the abstract. References, Words in Tables, Captions/Legends, Figure and Figure captions/legends are excluded from the word limits.

Please note that papers submitted for Special Issue volumes should also not exceed 6000 words.

As of December 2019, *JARID* no longer accepts Book Reviews.

4. PREPARING THE SUBMISSION

Use of Language

The language used to describe disability differs across countries, cultures and disciplinary fields, and continues to evolve. All manuscripts submitted to JARID must use language that promotes the value of all people as full members of our shared society. Pejorative language inclusive of euphemisms must not be used. For JARID this includes the use of older language that has been used to describe people with intellectual disabilities such as "retarded", "handicapped", or "mentally handicapped". Using any terms which are offensive, or patronising may lead to rejection of your submitted manuscript.

JARID recommends using person-first and/or identity-first language thoughtfully and appropriately. For example, the language used to describe both people with intellectual disabilities and autistic people has evolved based on recent advocacy efforts. When referring to people with autism, it is acceptable to use either identity-first language (e.g., "autistic people") or person-first language (e.g., people with autism"), while identity-first language is not used to describe people with intellectual disabilities, where person-first language is preferred. Thus, people with intellectual disabilities should be referred to as people with intellectual disabilities.

We have consulted with over 40 self-advocates through Learning Disability England which included the North West Self-Advocacy Group, as well as Self-Advocacy Together and asked them what language we should use when writing about people with intellectual disabilities.

People with intellectual disabilities said that they do not like to be referred to by acronyms or abbreviations. Authors must therefore not use an abbreviation to describe intellectual disabilities such as "ID" or "LD". Instead, use person-first language such as children, teenagers, adults, or people with intellectual disabilities, avoiding acronyms or abbreviations.

The terms "learning disabilities" and "learning difficulties", though used in some countries to refer to people with intellectual disabilities, can cause confusion among readers. These terms are not used by the journal to refer to people with intellectual disabilities. Authors must only use the term "learning disabilities or difficulties" where this refers to a specific learning disability/disorder– such as a specific learning difficulty in reading, written expression or mathematics. **If "learning disabilities" or "learning difficulties" are used, authors must not use an abbreviation.**

Free Format Submission

Journal of Applied Research in Intellectual Disabilities now offers Free Format submission for a simplified and streamlined submission process. Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, discussion, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.
- An ORCID ID, freely available at https://orcid.org. (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address. (Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)
    - Statements relating to our ethics and integrity policies, which may include any of the following (Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):
        - data availability statement
        - funding statement

- conflict of interest disclosure
- ethics approval statement
- patient consent statement
- permission to reproduce material from other sources
- clinical trial registration

Parts of the Manuscript

Submissions via the new Research Exchange portal can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx) or LaTex (.tex) formats.

If submitting your manuscript file in LaTex format via Research Exchange, select the file designation "Main Document - LaTeX .tex File" on upload. When submitting a LaTeX Main Document, you must also provide a PDF version of the manuscript for Peer Review. Please upload this file as "Main Document - LaTeX PDF." All supporting files that are referred to in the LaTeX Main Document should be uploaded as a "LaTeX Supplementary File."

Cover Letters and Conflict of Interest statements may be provided as separate files, including in the manuscript, or provided as free text in the submission system. A statement of funding (inlcuding grant numbers, if applicable) should be inlcuded in the "Acknowledgements" section of your manuscript.

Title page

The title page should contain:
i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's **best practice SEO tips**);
ii. A short running title of less than 50 characters;
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Acknowledgments.

Authorship

On initial submission, the submitting author will be prompted to provide the email address and country for all contributing authors.

The Research Exchange submission system will extract listed affiliations from the manuscript and then ask the submitting author to verify each author's affiliation institution(s). Authors are encouraged to include the complete affiliation addresses in the manuscript (Institution Name, Country, Department Name, Institution City, and Post Code). When verifying their institution, authors will also be asked to locate their base institution only (not necessarily the department or school).

Please refer to the journal's authorship policy in the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Main Text File

As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.
The main text file should be presented in the following order:

i. Title, abstract and key words;
ii. Main text;
iii. References;
iv. Tables (each table complete with title and footnotes);
v. Figure legends;
vi. Appendices (if relevant).

Figures and supporting/supplemental information should be supplied as separate files. For more information on prearing supporting/supplemental information, **click here**.

Abstract

All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. We kindly request that authors place the abstract and title at the beginning of the main manuscript document.

Keywords

Please provide up to six Keywords to aid indexing.

References

References should be prepared according to the *Publication Manual of the American Psychological Association* (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. For more information about APA referencing style, please refer to the **APA FAQ**. Note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one, and a DOI should be provided for all references where available.

Journal article

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, *159*, 483–486. doi:10.1176/appi.ajp.159.3.483

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from **http://www.youtube.com/watch?v=Vja83KLQXZs**

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive â€“ the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Additional Files

Appendices

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Supporting/Supplemental Information

Supporting/Supplemental information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.
Click here for Wiley's FAQs on supporting/supplemental information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

The following points provide general advice on formatting and style.

- **Spacing:** Manuscripts should be double spaced with a wide margin.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

Wiley Author Resources

Manuscript Preparation Tips: Wiley has a range of resources for authors preparing manuscripts for submission available **here**. In particular, authors may benefit from referring to Wiley's best practice tips on **Writing for Search Engine Optimization.**

Article Preparation Support
Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design â€“ so you can submit your manuscript with confidence.

Also, check out our resources for **Preparing Your Article** for general guidance about writing and preparing your manuscript.

Video Abstracts

A video abstract can be a quick way to make the message of your research accessible to a much larger audience. Wiley and its partner Research Square offer a service of professionally produced video abstracts, available to authors of articles accepted in this journal. You can learn more about it by **clicking here**. If you have any questions, please direct them to **videoabstracts@wiley.com**.

5. EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

Peer Review and Acceptance

Manuscripts are judged on the significance of the contribution to the literature, the quality of analysis and the clarity of presentation. Papers are expected to demonstrate originality and meaningful engagement with the global literature.

Except where otherwise stated, manuscripts are double-blind peer reviewed by anonymous reviewers in addition to the Editor. Ensure that all personally identifiable information is removed from your manuscript before you upload it to help protect your identity through the peer review process. Authors are asked not to post information about their submitted manuscripts to social media or websites until a final decision about the paper has been made; again, the reason for this is to help protect the double-blind peer review process. Authors who do not work in such a way as to help maintain the double-blind peer review process may have their manuscript rejected.

Final acceptance or rejection rests with the Editor-in-Chief, who reserves the right to refuse any material for publication or to edit any contribution to ensure that it conforms with the requirements of the journal

In-house submissions, i.e. papers authored by Editors or Editorial Board members of the title, will be sent to Editors unaffiliated with the author or institution and monitored carefully to ensure there is no peer review bias.

Wiley's policy on the confidentiality of the review process is **available here.**

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Wiley believes that no valuable research should go unshared. This journal participates in Wiley's Refer & Transfer program. If your manuscript is not accepted, you may receive a recommendation to transfer your manuscript to another suitable Wiley journal, either through a referral from the journal's editor or through our Transfer Desk Assistant.

Human Studies and Subjects

For manuscripts reporting studies that involve human participants, including but extending beyond medical research, a statement identifying the ethics committee that approved the study and confirmation that the study conforms to recognized standards is required, for example: **Declaration of Helsinki**; **US Federal Policy for the Protection of Human Subjects**; or **European Medicines Agency Guidelines for Good Clinical Practice**. It should also state clearly in the text that all persons gave their informed consent prior to their inclusion in the study.

Patient anonymity should be preserved. Photographs need to be cropped sufficiently to prevent human subjects being recognized (or an eye bar should be used). Images and information from individual participants will only be published where the authors have obtained the individual's free prior informed consent. Authors do not need to provide a copy of the consent form to the publisher; however, in signing the author license to publish, authors are required to confirm that consent has been obtained. Wiley has a **standard patient consent form** available for use.

Clinical Trial Registration

The journal requires that clinical trials are prospectively registered in a publicly accessible database and clinical trial registration numbers should be included in all papers that report their results.

Clinical trials should be reported using the CONSORT guidelines available at **www.consort-statement.org**. A CONSORT checklist should also be included in the submission material (**www.consort-statement.org**).

The Journal encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: **www.clinicaltrials.org**, **www.isrctn.org**.

Authors are asked to include the name of the trial register and the clinical trial registration number at the end of the abstract. If the trial is not registered, or was registered retrospectively, the reasons for this should be explained.

Conflict of Interest

The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Authorship

The list of authors should accurately illustrate who contributed to the work and how. All those listed as authors should qualify for authorship according to the following criteria:

1. Have made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; and
2. Been involved in drafting the manuscript or revising it critically for important intellectual content; and
3. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; and
4. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section (for example, to recognize contributions from people who provided technical help, collation of data, writing assistance, acquisition of funding, or a department chairperson who provided general support). Prior to submitting the article all authors should agree on the order in which their names will be listed in the manuscript.

Data Sharing and Data Accessibility

The journal encourages authors to share the data and other artefacts supporting the results in the paper by archiving it in an appropriate public repository. Authors should include a data accessibility statement, including a link to the repository they have used, in order that this statement can be published alongside their paper.All accepted manuscripts may elect to publish a data availability statement to confirm the presence or absence of shared data. If you have shared data, this statement will describe how the data can be accessed, and include a persistent identifier (e.g., a DOI for the data, or an accession number) from the repository where you shared the data. Sample statements are available on Author Services. If published, statements will be placed in the heading of your manuscript.

Publication Ethics
This journal follows the core practices of the **Committee on Publication Ethics (COPE)** and handles cases of research and publication misconduct accordingly (**https://publicationethics.org/core-practices**)"

Note this journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Read Wiley's Top 10 Publishing Ethics Tips for Authors **here**. Wiley's Publication Ethics Guidelines can be found **here**.

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Standard **re-use and licensing rights** vary by journal. Note that **certain funders** mandate a particular type of CC license be used. This journal uses the CC-BY/CC-BY-NC/CC-BY-NC-ND **Creative Commons License**.
Self-Archiving Definitions and Policies: Note that the journal's standard copyright agreement allows for **self-archiving** of different versions of the article under specific conditions.

Appendix D: Mixed Methods Appraisal Tool (MMAT)

Appendix E: Algorithm for selecting the study categories to rate in the MMAT

Appendix F: Data Extraction Form

Authors	Year	Title	Aims	Methodology and design	Participants	Outcome measures	Results	Key findings

Appendix G: Table of Papers included in Themes and Subthemes

Themes	Subtheme	Papers included in the theme
1. Reduction of Behaviours that Challenge		Conway et al. (2019), Inchley-Mort et al. (2014), Lewis et al. (2021), McClean et al. (2007), McClean et al. (2012), McGill et al. (2018), McKim et al. (2021), McKenzie et al. (2018b), McKenzie et al. (2021), Toogood et al. (2011), Webber et al. (2017), West et al. (2010).
2. Reduction of the Use of Psychotropic Medication		Conway et al. (2019), Gerrard et al. (2019), McClean et al. (2007).
3. Improvements in Quality of Life	3.1 Positive Enhancements to Mental Health and Wellbeing	Lewis et al. (2021), McClean et al. (2007) McClean et al. (2012), McKim et al. (2021), McKenzie et al. (2018b)
	3.2 Relationships with Staff and Families	McClean et al. (2012), McKim et al. (2021), McKenzie et al. (2018a), McKenzie et al. (2018b), McKenzie et al. (2021).
	3.3 Additional Activities and Occupation in the Community	Lewis et al. (2021), McClean et al. (2007), McClean et al. (2012), McGill et al. (2018), McKim et al. (2021), McKenzie et al. (2018b), McKenzie et al. (2021), West et al. (2010).
4. Changes in the Extent of Support Required	4.1 Support Reduction for Behaviours that Challenge	McClean et al. (2007), McKenzie et al. (2018b), West et al. (2010).
	4.2 Increased Support Networks and Quality of Support	Inchley-Mort et al. (2014), McClean et al. (2007), McGill et al. (2018), McKenzie et al. (2018a), McKenzie et al. (2021), Toogood et al. (2011).
5. Elements of Positive Behaviour Support Which Assisted Changes in Outcomes Post-Implementation	5.1 Increased Understanding of People with Behaviours that Challenge	McClean et al. (2007), McGill et al. (2018), McKim et al. (2021), McKenzie et al. (2018a), McKenzie et al. (2018b), McKenzie et al. (2021).
	5.2 Contrast with Negative Experiences	McKenzie et al. (2018a), McKenzie et al. (2018b), Webber et al. (2017).

Appendix H: Documentation of Ethical Approval (University and Health Research Authority)

Appendix I: Recruitment Email

Hello,

Thank you for showing interest in my research. I am looking to interview Health Care Assistants working in inpatient care on their experiences of using PBS. The interview may last up to 60 minutes.

The inclusion criteria:

- 18+ years old
- English speaker
- Working as a health care assistant at Townend for more than six months
- Have received PBS training
- Have experience using PBS

I have attached an information sheet, please read this for more information on the study.

If you would like to participate, please fill in and return the consent form and demographic questionnaire and return them to me via email.

If you have any questions at all, please email me and I would be happy to answer them.

Hope to hear from you soon,

Natasha Rogers

Appendix J: Research Flyer

Version 4 28.09.21 298668

UNIVERSITY OF HULL | FACULTY OF HEALTH SCIENCES

Research Participants Needed

Do you care for adults with learning disabilities and behaviours that challenge?

We are interested in hearing your experiences of health care assistants who support adults with learning disabilities and behaviours that challenge.

What it is like working using Positive Behaviour support and how that influences your perceptions, values and attitudes?

This research is part of the Clinical Psychology doctorate at the University of Hull

What is involved?

A one to one interview will take place either face to face or online on Microsoft Teams

It will take around one hour and be audio recorded

Opportunity to reflect on your work experiences

All information will be kept confidential and anonymous

Results will be feedback after analysis

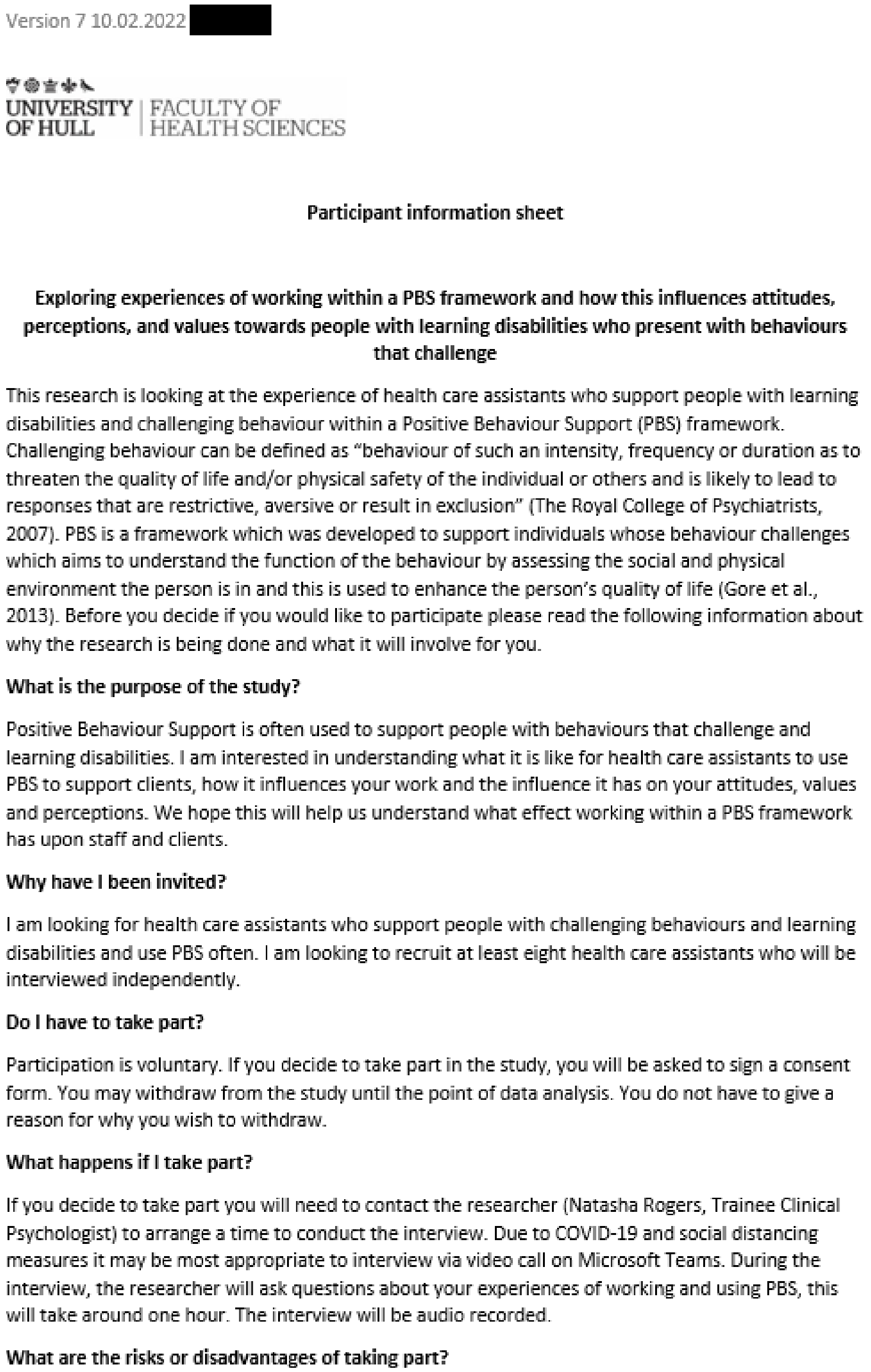
Do you want to find out more?

Please contact Natasha Rogers (lead researcher) for more information

You can contact Natasha on the phone: 07816369084

Or you can email her at: N.Rogers-2016@hull.ac.uk

Appendix K: Participant Information Sheet



Version 7 10.02.2022 [redacted]

UNIVERSITY OF HULL | FACULTY OF HEALTH SCIENCES

Participant information sheet

Exploring experiences of working within a PBS framework and how this influences attitudes, perceptions, and values towards people with learning disabilities who present with behaviours that challenge

This research is looking at the experience of health care assistants who support people with learning disabilities and challenging behaviour within a Positive Behaviour Support (PBS) framework. Challenging behaviour can be defined as "behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion" (The Royal College of Psychiatrists, 2007). PBS is a framework which was developed to support individuals whose behaviour challenges which aims to understand the function of the behaviour by assessing the social and physical environment the person is in and this is used to enhance the person's quality of life (Gore et al., 2013). Before you decide if you would like to participate please read the following information about why the research is being done and what it will involve for you.

What is the purpose of the study?

Positive Behaviour Support is often used to support people with behaviours that challenge and learning disabilities. I am interested in understanding what it is like for health care assistants to use PBS to support clients, how it influences your work and the influence it has on your attitudes, values and perceptions. We hope this will help us understand what effect working within a PBS framework has upon staff and clients.

Why have I been invited?

I am looking for health care assistants who support people with challenging behaviours and learning disabilities and use PBS often. I am looking to recruit at least eight health care assistants who will be interviewed independently.

Do I have to take part?

Participation is voluntary. If you decide to take part in the study, you will be asked to sign a consent form. You may withdraw from the study until the point of data analysis. You do not have to give a reason for why you wish to withdraw.

What happens if I take part?

If you decide to take part you will need to contact the researcher (Natasha Rogers, Trainee Clinical Psychologist) to arrange a time to conduct the interview. Due to COVID-19 and social distancing measures it may be most appropriate to interview via video call on Microsoft Teams. During the interview, the researcher will ask questions about your experiences of working and using PBS, this will take around one hour. The interview will be audio recorded.

What are the risks or disadvantages of taking part?

You will be asked questions about your experiences at work, and you may find this distressing if you have had some difficult or upsetting experiences. Please consider if you would feel comfortable discussing your experiences. If you find anything distressing, you can be offered a break or to end the interview. At the end of the interview, you will be provided with information on relevant support if you need it. The interview will require your time and this can take place outside of work or in work time with approval from your line manager. It may be more convenient to have the interview at the beginning or at the end of the shift to minimise disruption or when you are not at work.

What are the possible benefits of participating in the study?

It is hoped that the opportunity to discuss your experiences will allow you to reflect on your work. Furthermore, the research will contribute to understanding how PBS is used within services and what impact it has on staff and people with learning disabilities.

What if I have any questions or concerns?

If you have any questions or concerns about the research, you are welcome to contact the researcher and supervisors to discuss these and they will do their best to resolve the problem. The contact details are provided at the end of the information sheet.

Will my information be kept confidential?

The information will be pseudonymised and remain confidential. Any information that could be used to identify you will not be included in the write-up. Information obtained in this study will only be used for this study. Personal data will be kept securely in accordance with data protection guidelines and will only be available to the immediate research team. Personal data will be stored for 6 months after the completion of the project and research data will be stored for 10 years after the completion of the project. After this time the data will be destroyed. The recording will be destroyed once transcribed. If you disclose something that suggests that you or someone else is at risk of harm, then confidentiality must be broken, and the researcher will need to contact the appropriate services to ensure people are safe. Where possible, the researcher will discuss this with you. If it is an imminent safety concern the interview will be terminated. If a safeguarding concern is discovered after the interview, for example in transcription, the safeguarding policies will be followed also.

How will my information be used?

The data used will only be data that is needed to do the research. Your name and contact details will be stored in order to contact you about the study and will be deleted following the completion of the data collection.

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you**.** Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Information Compliance Manager (dataprotection@hull.ac.uk). If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What are my choices about my patient data?

You can stop being part of the study at any time, without giving a reason.

Withdrawing from the study will not affect you in any way. You may withdraw your data from the study and your data will be destroyed. However, participant data cannot be withdrawn from the study once the data has been pseudonymised and analysed. You have up to 72 hours after the completion of the interview to withdraw your data.

Where can I find out more about how my information is used?

You can find more information by

Contacting the principal investigator by emailing: N.Rogers-2016@hull.ac.uk

Or at the following website: www.hra.nhs.uk/information-about-patients/

What happens to the results of the study?

The results of the study will be written up as part of a doctorate research thesis and also in a research paper that will be submitted for publication in an academic journal. This will include some direct quotes from your interview, which will be pseudonymised. None of your personal data will be included in the thesis or research paper. After completion, I can communicate the results of the study with you if you wish.

Who is organising and funding the research?

The research is being undertaken as part of a Doctorate in Clinical Psychology at the University of Hull.

Who has reviewed the study?

This research has been reviewed and approved by the Faculty of Health Sciences ethics committee at the University of Hull and also by the Health Research Authority.

Further information and Contact information

If you have any questions or would like any further information about the research, please contact the lead researcher:

Natasha Rogers
Telephone: [redacted]
E-mail: [redacted]

Who can I contact if I have a complaint?

If you have an issue with how the researchers have handled your information you can contact the research team at the University of Hull using the research supervisor's details below:

Dr Nick Hutchinson
Telephone: [redacted]
Email: [redacted]

Thank you for reading the information and for considering participating in the research study

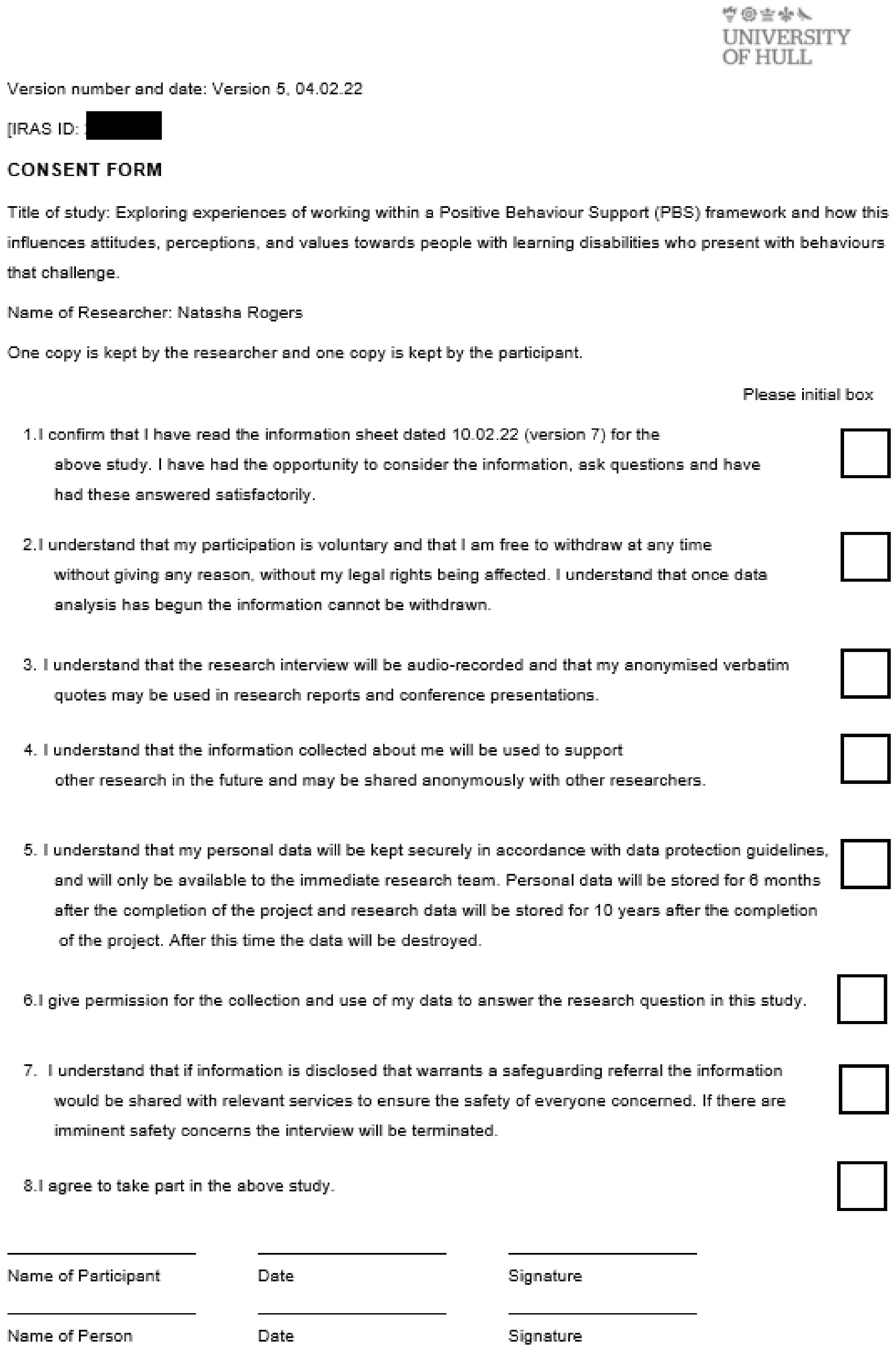
If you are interested in participating in the study, please complete the consent form and return to the researcher. You will have the opportunity to ask questions and arrange an interview time that is best for you.

References

Gore, N. J., McGill, P., Toogood, S., Allen, D., Hughes, J. C., Baker, P., Hastings, R. P., Noone, S. J., & Denne, L. D. (2013). Definition and scope for positive behavioural support. *International Journal of Positive Behavioural Support, 3*(2), 14-23.

Royal College of Psychiatrists & British Psychological Society (2007). Challenging behaviour: a unified approach. College Report CR144. London: Royal College of Psychiatrists*, British Psychological Society and Royal College of Speech and Language Therapists*.

Appendix L: Participant Consent Form



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Version number and date: Version 5, 04.02.22

[IRAS ID: [redacted]

CONSENT FORM

Title of study: Exploring experiences of working within a Positive Behaviour Support (PBS) framework and how this influences attitudes, perceptions, and values towards people with learning disabilities who present with behaviours that challenge.

Name of Researcher: Natasha Rogers

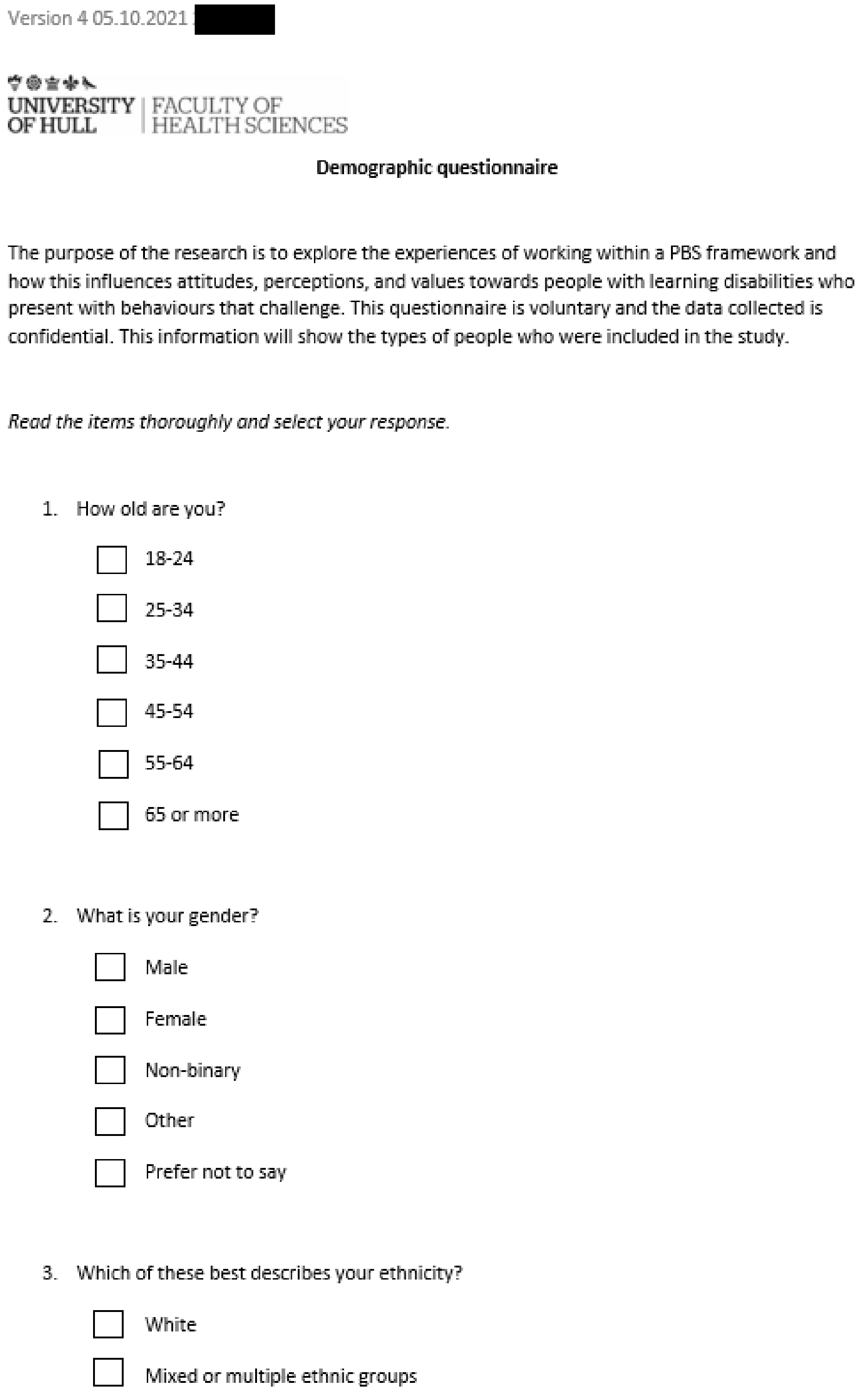
One copy is kept by the researcher and one copy is kept by the participant.

Please initial box

1. I confirm that I have read the information sheet dated 10.02.22 (version 7) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. I understand that once data analysis has begun the information cannot be withdrawn. ☐
3. I understand that the research interview will be audio-recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations. ☐
4. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐
5. I understand that my personal data will be kept securely in accordance with data protection guidelines, and will only be available to the immediate research team. Personal data will be stored for 6 months after the completion of the project and research data will be stored for 10 years after the completion of the project. After this time the data will be destroyed. ☐
6. I give permission for the collection and use of my data to answer the research question in this study. ☐
7. I understand that if information is disclosed that warrants a safeguarding referral the information would be shared with relevant services to ensure the safety of everyone concerned. If there are imminent safety concerns the interview will be terminated. ☐
8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person	Date	Signature

Appendix M: Demographic Questionnaire



Version 4 05.10.2021 [redacted]

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Demographic questionnaire

The purpose of the research is to explore the experiences of working within a PBS framework and how this influences attitudes, perceptions, and values towards people with learning disabilities who present with behaviours that challenge. This questionnaire is voluntary and the data collected is confidential. This information will show the types of people who were included in the study.

Read the items thoroughly and select your response.

1. How old are you?
   - ☐ 18-24
   - ☐ 25-34
   - ☐ 35-44
   - ☐ 45-54
   - ☐ 55-64
   - ☐ 65 or more

2. What is your gender?
   - ☐ Male
   - ☐ Female
   - ☐ Non-binary
   - ☐ Other
   - ☐ Prefer not to say

3. Which of these best describes your ethnicity?
   - ☐ White
   - ☐ Mixed or multiple ethnic groups

☐ Asian or Asian British

☐ Black, African, Caribbean, or Black British

☐ Other ethnic group:

Please specify ____________________________________

☐ Prefer not to say

4. What is your job title?

____

5. How long have you worked with people with Learning Disabilities?

____

6. How long have you worked in this service?

____

7. How many hours of PBS training have you had?

☐ 0-1 hours

☐ 1-2 hours

☐ 2-3 hours

☐ 4-5 hours

☐ 5+ hours

8. Who delivered the training?

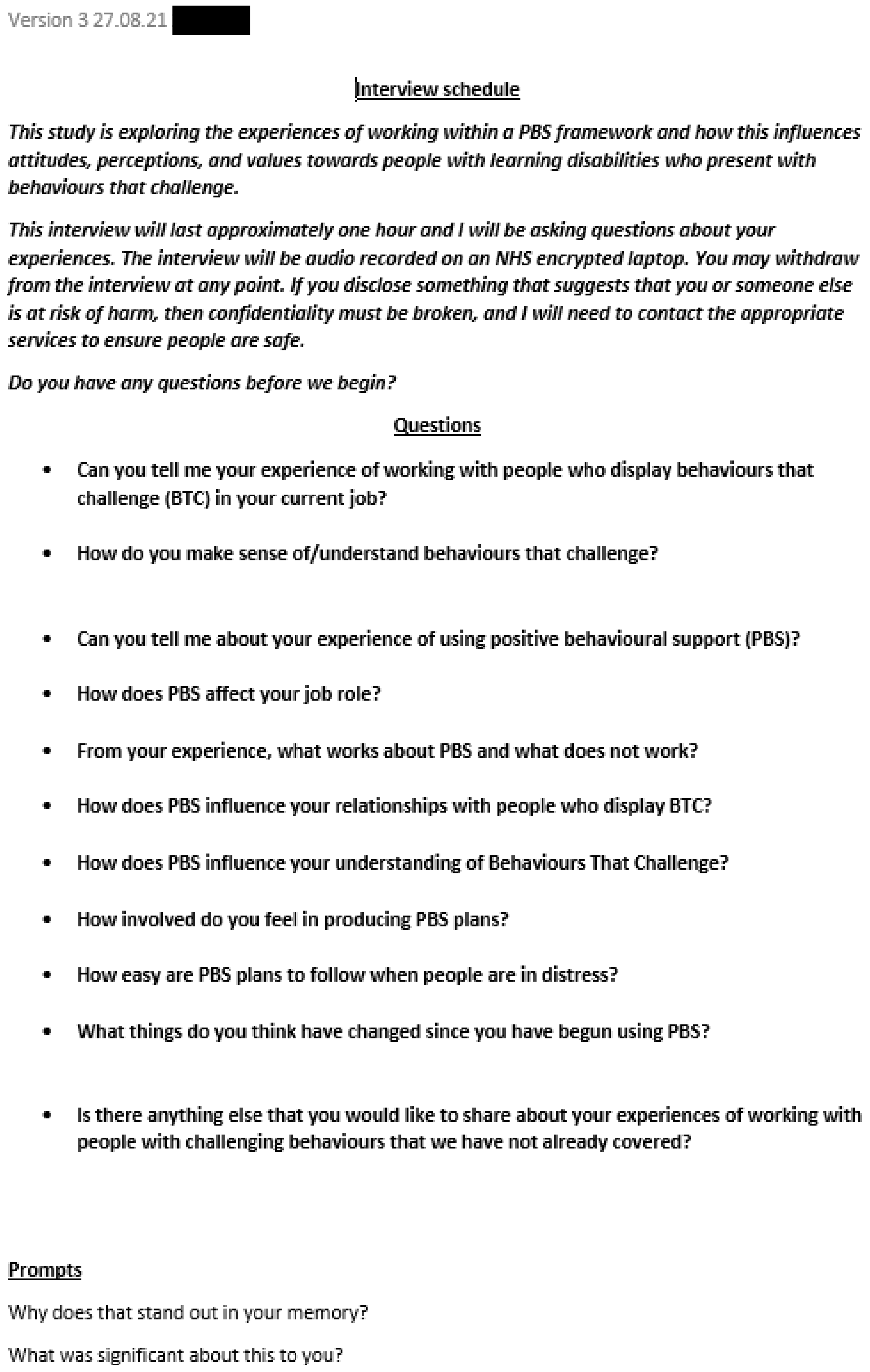
☐ In house training

☐ Accredited PBS training

9. How long have you been using PBS in your work?

____

Appendix N: Interview Schedule



Version 3 27.08.21 [redacted]

Interview schedule

This study is exploring the experiences of working within a PBS framework and how this influences attitudes, perceptions, and values towards people with learning disabilities who present with behaviours that challenge.

This interview will last approximately one hour and I will be asking questions about your experiences. The interview will be audio recorded on an NHS encrypted laptop. You may withdraw from the interview at any point. If you disclose something that suggests that you or someone else is at risk of harm, then confidentiality must be broken, and I will need to contact the appropriate services to ensure people are safe.

Do you have any questions before we begin?

Questions

- **Can you tell me your experience of working with people who display behaviours that challenge (BTC) in your current job?**
- **How do you make sense of/understand behaviours that challenge?**
- **Can you tell me about your experience of using positive behavioural support (PBS)?**
- **How does PBS affect your job role?**
- **From your experience, what works about PBS and what does not work?**
- **How does PBS influence your relationships with people who display BTC?**
- **How does PBS influence your understanding of Behaviours That Challenge?**
- **How involved do you feel in producing PBS plans?**
- **How easy are PBS plans to follow when people are in distress?**
- **What things do you think have changed since you have begun using PBS?**
- **Is there anything else that you would like to share about your experiences of working with people with challenging behaviours that we have not already covered?**

Prompts

Why does that stand out in your memory?

What was significant about this to you?

Why did you decide to do this?

What do you mean by [term or phrase]?

Can you expand upon this?

Can you give examples?

Could you describe this experience in more detail?

How did others respond to that?

Why does that matter?

What was your reasoning for this?

Appendix O: Example Annotated Transcript Section

Experiential Statement	Transcript	Exploratory notes
	Interviewer: The first question is quite broad, it's about your experiences working with behaviours that challenge in general, what's it like?	
Working with behaviours that challenge is rewarding	**Mary**: what's it like? It's erm it's rewarding, erm it's frustrating at times, it's challenging mainly physically, but yeah no overall it's rewarding. I've done this job for 35 years working with LD with people who present with challenging behaviour erm within day services and within this setting [inpatient] erm so it's sort of a different approach to PBS's and the way we support people both, you know there is similarities but there is vast differences	The work is rewarding despite challenges Lots of experience working in this area Different way to support people in inpatient settings
	Interviewer: so what about it is rewarding?	
Not changing a person and their behaviours but changing her approach Rewards come from reductions in behaviours that challenge and restrictions	**Mary**: What's rewarding? It's seeing people who come in with some behaviours that are really challenging, and I've always said and always say, you can't, you *can't* change that person you can change the behaviours but you can manage them, so finding a way that you can manage them and bringing in a PBS and seeing a result where that behaviour is less frequent or we can manage it quicker erm *that's* the rewarding part. We've got two patients at the moment who we've put in a *lot* of work on and	Long held belief? Not about changing the person but changing the approach A result when there is a reduction in behaviours and that is rewarding

It’s a slow process and staff need to persevere Staff may feel hopeless but things do improve	it’s been so rewarding to see one of them who was in CAFO [Care Away From Others], locked CAFO, you’ve probably heard other people say it, naked, faeces everywhere, banging his head, self-injurious behaviour, injuring staff, to *now* that happens rarely, you know he was in that position and another unit for and here for two/three years but we’d *slowly* with PBS’s, with support from staff, with determination, with all of that he’s just now gone out on leave, so from one extreme to the other and that’s all- that’s the rewarding bit, the same with the guy on here whose behaviour when he first came in was really challenging, like again we don’t change that behaviour, but now what could have lasted for two hours we can now talk down in twenty [minutes] so again, again you know challenging behaviour suck as wrecking furniture, you know or becoming heightened and saying he’s going to assault staff again twenty minutes we can talk him down now and *that’s* the reward seeing people going from here and back into the community, people go “oh there behaviour is ooooh they’ll never be able to do that” yeah we’ve seen that and we’ve done that as a team, I think we are very good at it	Lots of work goes into the support Change from behaviour that was challenging and the use of restrictions to the behaviour happening less frequently and less restrictions A slow process, change does not occur quickly, staff have to support and persevere Seeing change is the reward The behaviours not changed just managed differently so does not last as long- rewarding Rewarding to see people go back into the community Sometimes there is hopelessness? Evidence that change happens?

Appendix P: Full Quotations for Subordinate Themes

Superordinate Themes	Subordinate Themes	Full Quotes for Subordinate Themes included in the Main Text
1. Understanding Behaviours that Challenge	1.1 Developing a Holistic Perspective	*“Like I say I was new to care when I came on the inpatient unit, initially it was like woah, what’s going off? But once you understand, yeah you do feel sympathy, yeah you feel sympathetic you understand more you realise that something’s going on it’s not just, they’re not doing it to get at you or, there’s usually a reason or a motivation to change something or yeah, and so it’s yeah trying to deal with it and manage the behaviour” (Roger)*
		“If I could look back now to the previous job, if someone was acting in a challenging way I’d probably have quite a two-dimensional way of looking at it and think they’re acting this way because that’s who they are, whereas now I’d understand and I can see it from a whole other perspective so I’d say it’s given me a lot more empathy and compassion, not like I was unempathetic but I can really just see a total just other way now to why people act the way they do because of going through so many PBS’s [pause] I think it probably just makes me more maybe aware of what could be happening and what could happen” (Dave)
		“It was fine because you understood, well, in general that it wasn’t a targeted thing at you in general, it was a reaction to their environment or to particular stressors or triggers erm, things that were out of their control and it was just their reaction to it so as I say that’s probably why I didn’t feel at risk or unsafe, because generally there was something bothering them and you wanted to find out what it was and what you could do to make it better really and avoid that happening again” (Roger)
	1.2 Discourses, Beliefs and Attitudes	*“They are allowed to get angry, they are allowed to get upset and who are we to say no you can’t? But as soon as that person, that patient gets annoyed or gets upset it’s ooo it’s a behaviour, ooo it’s a challenge, it’s not it’s an expression of how they are feeling” (Jenny)*

		"You know someone's in the communal lounge their behaviour could be different than what it would be you know say if they're sat in the dining room because you know again those social constructs of this is how you behave in a certain place really has an impact on someone, and also how we as staff believe that they should behave in that situation if that makes sense, we've got to really make sure that we don't push our own morals onto people I think that's really important" (Emma)
		"That's when you see maybe [pause] challenging behaviour within some sort of staff groups, you can come on and think right an incident happens and you can sort of guess who was on there because it's a staff attitude thing, I don't think that's a lie but yeah there's definitely staff that don't want to pursue and don't want to see maybe why that behaviour is happening it's just a "stop it", do you know what I mean?" (Mary)
	1.3 Making Sense Through the Analysis	*"That behaviour is there for a reason erm whether that person can't verbalise properly why they are doing that we have to sort of try and unpick and that's by doing a lot of you know, a lot of watching, a lot of listening, a lot of talking to other people, erm but I think you never- that behaviour is there for a reason, whether that's physical whether that's mental whether it's you know [pause] learnt" (Mary)*
		"I remember when he first came in, it was in his PBS plan where we had to give him pressure but he used to scream the night, the whole night he would scream in his bedroom and he'd either want his feet massaging or he'd want he'd grab you and put you over him, he used to hurt as well, he'd put you over him lay you over him and then pressure you down, it was just the pressure, a lot of them like that pressure too, I don't know what it does? It must make them feel, I don't know, safe? I suppose, erm I'm not used to things like that but [pause] they are all a little bit different so I suppose it depends on the behaviour" (Yelsel)

		“Because we just assuming what we do helps because it maybe de-escalates a situation but that maybe doesn’t help their mental health, you know we might go in and de-escalate a situation but if we don’t know what they want, they may be thinking oh they’re just going to do this anyways so I might as well just stop this behaviour or whatever, but we’re not actually dealing with the issue, if that makes sense? For example, if someone starts headbutting a wall you know we might go in and restrain them, they might go, okay I don’t like being restrained so I’ll stop, but maybe for that person it might be a, I need to do this but give me a cushion, because there might be a sensory need there” (Emma)
2. Using PBS as a Health Care Assistant	2.1 The Involvement of HCAs in the Development and Implementation of PBS Plans	“*Well I think it helps when you work on the ground to see what actually happens with the patients, we know obviously more than what those sat in the offices, the patient does see them but because they’re not on the floor all the time the information they get is what we’ve put initially isn’t it” (Yelsel)*
		“Oh god yes yeah yeah and [PBS Coach] is pretty good because even if they have an update they will email all of us and say I have updated the plan, have a read, what do you think? And then there’s obviously an opportunity to go up to them and say actually I’m not quite sure what you mean by that or can we add this? Or yeah, so there’s opportunities and that’s nearly sort of every month, yeah it’s really frequent” (Jenny)
		“Sometimes you know we have the opportunity to sort of write down you know I don’t agree with this or whatever but because of how busy we can be not everybody gets that opportunity so then what you have is some people’s opinions but not the whole staff teams opinions so that can often cause like the PBS to shift in a certain way, you know like especially if you’ve got a lot of people with the same kind of opinion that get in there and say you know this is what we think it will take the PBS in a certain different way whereas we, a larger portion of people, don’t agree or sometimes aren’t on shift or don’t have time or you know don’t have that option to have that input” (Emma)

		"I do think having the PBS plan is really good for having some guidance, and sometimes that's all it can be good for is just a bit of guidance, they don't always have to follow everything on that plan because not everything works most of the time, but just having that guidance and sometimes its good to give you a little bit of knowledge about that patient, you know their likes and dislikes and things like that, their history, it can give quite a good background for that person" (Emma)
		"I think sometimes a person in a different environment behaves in a different way, you know what you get sometimes when a person first comes in and they change obviously, so no I think I'd rather go on face value and working with that person, alongside with the paperwork side of it, alongside the PBS, but I wouldn't read a PBS and go "right okay, that that's what I'm doing" do you know what I mean? You have to you have to get to know that person as well as the things in place because again people are different with different people with different environments different things" (Mary)
		"People just talking sort of through the PBS and sort of admitting that the person is still a patient and a person you just can talk to, they kind of rely too heavily on that and their interactions then seem a bit like clinical and not very like person-centred or, although the PBS is entirely person-centred they are just talking to them as like statistics on a page as opposed to 'you're a person in front of me and let's just talk'" (Dave)
	2.2 PBS Intertwined in HCA Work	*"So it was nice to have something a bit more formal like PBS to actually refer to, to think right it's not just about me using my initiative there's actually something here written up by doctors and psychiatrists that is like the gold standard of this will work so do this. So it's given me a lot of confidence because you're not just winging it or just assessing it in a situation you actually have something solid to refer back to, to sort of back you up or guide you" (Dave)*

		"I think again from the information we gained and the knowledge erm I just worked more proactively with the person with a better understanding of the approaches so that probably was working with the PBS but I probably wasn't conscious of that at the time it was just oh we've got this information erm and yeah working with it, it would be using the PBS but I can't say that I was that conscious that I was doing it in a positive behavioural support way it was just I have knowledge about this person now" (Roger)
		"I had handed over to [PBS Coach] that there was something not right, there was something in his presentation that wasn't right there was something er in just how he spoke, how he communicated and he had changed, and that was sort of on the Monday and by the Wednesday he was assaulting staff and ended up in seclusion, so those triggers where already there it's just picking up and acting on them" (Jenny)
		"I think it's pretty much has always been like that, you know I'm not one of those "oh I've done this for years" but yeah we've always put something like that in place, so even going back to the 80s do you know I think it's just it's become a thing it's become you know "this is what we have to do, this helps" you know? So I think it's promoted more that it was before. But I think yeah the actual content it think has always sort of been pretty much the same, it's probably come on a bit but yeah" (Mary)
	2.3 Successes and Positive Challenges	*"Now he is a totally different man, erm, he just lives well not lives he's on the units and the same as anyone else he can come and go from his room as he pleases so that's really nice to know that his life has literally taken a complete turn. Erm, and same with all patients with challenging behaviour eventually they'll kind of they'll just click and you'll start, both you and the patient, just getting each other more and you'll just make so much progress with the relationship" (Dave)*

		"It's knowing what actions to take to stop it escalating any further really, so I'm grateful for it actually being in place [laughs] because a lot of the time I do work independent and on my own without support staff so I need to have that confidence to be able to pick up them clues of someone getting fed up or getting agitated and de-escalate before it gets to the next stage, because if I'm in the community with someone shopping or going for a walk I haven't got a staff team to back me up, so I've got to be able to have the confidence to be able to have the communication skills with that patient to be able to make sure that I can let them know that they are safe and it's okay to get fed up but you know lets sort of make our way back now [laughs] yeah" (Jenny)
		"The job itself [pause] it challenges in me in the sense that I like doing this I like I like a challenge, I'm one of the people I think that works more on adrenaline, I like the more challenging person because I find it more rewarding to see that behaviour managed differently. Does that make sense?" (Mary)
	2.4 The Challenges of Working with BTC and Risk	*"If you're on there all week [sighs] your feet are killing you by the end of the week and it's mentally draining as well definitely" (Yelsel)*
		"We spend a lot of our lives with these people you know we're here three or four days a week for twelve hours a day you know we're here Christmases and birthdays all of that kind of thing we spend a lot of time with these people and you know you take on a lot of their stresses as well so sometimes you just need a vent you know, I know you do always have the option of supervision with people like [PBS Coach] and management and things like that and arranging with supervisors erm and I think that can be helpful, sometimes that doesn't work at all, sometimes you get to a point where you're so drained that you need to take time for yourself you know" (Emma)
		"I suppose it depends on if that person is punching someone you have to just kind of deal with that behaviour rather than looking at or observing the behaviour, sometimes you can kind of like observe a behaviour, that's a behaviour that concerns, depending on the severity of it and the risk around it so if for examples someone's going around picking things up off the floor or knocking things off a table the risk to themselves and others isn't necessarily high or severe, so maybe you can observe that behaviour for a little while

		longer, whereas if that patient is trying to scale the fence or trying to you know swallow batteries or anything like that you have to react to that behaviour before you can analyse it because you need to keep that person safe and the other people safe around them so, yeah so that's sometimes where you can't always look at the behaviour as it's happening you have to kind of retrospectively look at it" (Emma)
		"Challenging because you're trying to get through to someone just like through a door or a window, so if they choose not to listen to you or walk off you're kind of stuck really because you can't go in so you've got to rely on just your communication and you're sort of interpersonal skills to get a message across or maybe talk them down from something or reassure them or redirect them, you've only got verbal communication, or like I say if they choose to disengage then you've kinda lost. So that can be challenging." (Dave)
3. Relationships	3.1 A Consistent, Cohesive and Persistent MDT Approach	*"If you've got a cohesive staff team that are all on the same page, are all following the care plans, are all following the positive behavioural support plans, you know and understand them and why they've been doing it, then you've got consistency and consistency for our patients are key you know we have patients with autism, patients with learning disability, if you've got somebody coming in and saying one thing and another person saying another it's so confusing for us as staff let alone a patient" (Emma)*
		"Slowly with PBS's, with support from staff, with determination, with all of that he's just now gone out on leave, so from one extreme to the other and that's all- that's the rewarding bit, the same with the guy on here whose behaviour when he first came in was really challenging, like again we don't change that behaviour, but now what could have lasted for two hours we can now talk down in twenty [minutes] so again, again you know challenging behaviour suck as wrecking furniture, you know or becoming heightened and saying he's going to assault staff again twenty minutes we can talk him down now and that's the reward seeing people going from here and back into the community, people go "oh there behaviour is ooooh they'll never be able to do that" yeah we've seen that and we've done that as a team, I think we are very good at it" (Mary)

		“I mean obviously with the MDTs there will be challenges within MDT because every professional will have a different approach and there might be conflict there, erm they are the barriers that we have to overcome and try and sort of work together for the greater good and I think this is where the PBS comes in because it’s a multidisciplinary approach everyone agrees with that approach and it’s like a set of guidelines, rules and you know obviously a plan, a care plan of how to help that person, so if we stick to that everything’s fine. But there’s times when we review it and think, there’s times we did that and that didn’t work let’s try a different approach, but yes yeah, that’s been the biggest challenge I’ve sort of come up against here, as if the whole team has a different approach or opinion because they obviously see different things” (Jenny)
	3.2 Therapeutic Relationships	*“If you’re working from the PBS, is then really person-centred because your approach is sort of defined by [pause] you know I could read your [interviewer] PBS and I’ve read your entire history and your background, so I’m thinking of things “oh I won’t mention this sort of thing because I know that they do or don’t like this”, so I think it gives you a bit of a erm, just sort of a bit more of a knowledge on someone to know maybe the best way to sort of engage with them and just sort of gives you a bit more information on who they are so you can [pause] it probably helps you develop a relationship quicker because you know more about them you’ve got likes and dislikes or things that annoy them, you can sort of tailor your approach to that sometimes to er [pause] yeah to be a bit more person-centred with them” (Dave)*
		“I imagine a really good one because I feel like you can build a more therapeutic relationship with them and then they feel safer or they feel more confident in your skills, because obviously here it’s an LD [learning disability] service but we have varying levels of learning disability, with some people it’s profound and they don’t know when they’re doing something that could hurt them or hurt you, some people do know and I think it probably reassures them to know “oh I know if I do this I’ll be safe because he [Dave] knows this about me” (Dave)
		“It’s distressing and I make a point of when the alarms go off and because I work in activities and work predominantly on my own, I don’t want to be that

		initial team that goes rushing in to restrain because that breaks down that relationship [pause] you know the trust is gone and you can't get that back because from their point of view it's well you held me down you're not my friend I don't trust you anymore, and that's it, so from sort of a therapeutic relationship, I always go as sort of the second team, so if the first team needs relieving or whatever, by that time the person might be in a state where they are able to communicate and look for the rescuer" (Jenny)
		"It can be hard but that can come down to us being confident and erm sort of getting the point across that, yes empathy, empathy and compassion I think, understanding why that person's got upset and you know letting them know its not wrong to get upset, you know you're no different to the rest of us as human beings, people get upset, just because they take it to the next level or cannot control those emotions they shouldn't be penalised for that everyone is allowed to get upset, erm and it's getting that point across, its making them feel comfortable with that and just saying yeah I can empathise, yeah I can understand why you've got upset and we're here to help you to deal with that so yeah, communication that's the key [laughs], effective communication [laughs]" (Jenny)
	3.3 Patients Should be Involved More but There are Barriers	*"I just don't think it's as much as it should be, you know I think, and again it's very difficult because of the type patients we have in, patients coming in, in crisis situations, learning disabilities and the barriers of that and the barriers of autism and communication skills and things like that, you don't always have that opportunity to, but where you can I think there should be more involvement, you know you should be able to sit down with someone and say, when this happens what would you like us to do? How can we help you?" (Emma)*
		"I have the opportunity while they are focussing on something else it could be art and crafts, they are quite open to discussion because they're distracted and doing something else and they're comfortable and relaxed they'll discuss things that have upset them in the past and you know so it is that observation and writing notes and passing that information over and saying, actually while I was working with that person this morning they said they don't like the colour orange, right, that could be a major thing that needs to be put into the plan you

	know so [pause] yeah so it's the observations and the opportunities to sort of, like I said it's a bit sort of detective work, they're not open to the doctors because they doctor will come in and say, are you alright? Yes I'm alright. And that's it they don't relax enough to start being open." (Jenny)
	"Yeah I can't see why not yeah I think [pause] I think if they can see it's all about their best interests and a way of getting them off the inpatient unit and back into the community in a sustainable way were they will have staff that understands their likes and dislikes and what their trigger points are erm yeah it's got to be a good thing" (Roger)

Appendix Q: Additional Supporting Quotations for Subordinate Themes

Superordinate Themes	**Subordinate Themes**	**Additional Quotes for Subordinate Themes not Included in the Main Text**
1.	1.1	*"I think mostly would be my understanding just the why people act the way they do. I did a PBS training course on trauma and that was really interesting because it kind of opened my eyes to just trauma in general really I'd never known much about it but now I can realise there's so many different types of trauma that people have probably been involved in and that all contributes to the PBS, so now let's say it just gives me a better understanding of again why people act the way they do and why certain approaches will or won't work with specific people"* (Dave)
	1.2 Discourses, Beliefs and Attitudes	-
	1.3 Making Sense Through the Analysis	*"I always see a behaviour as a way or a method of communication so personally for myself I'll sort of analyse well a bit like the ABC isn't it, you know the antecedent behaviour consequence, so what's happened previous to that person getting upset or distressed? Was it avoidable? Was it our fault? So you sort of you are sort of breaking it down and evaluating the situation as it happens erm, then look at the person, right yes they are getting distressed, is there anything I can do as a professional that can alleviate that? Reduce that? Bring them back down to the level where they can understand and they can rationalise why they're getting upset, erm and then obviously afterwards when they've calmed down talk about it because there may be something that we maybe wouldn't necessarily observe, or take for granted, that is a trigger for them."* (Jenny)
		"It's sort of you know working with that individual in the way that the PBS is, so for example like recognising their triggers, and implementing a sort of, the de-escalation skills that are kind of identified in a PBS plan and erm and following sort of those activity suggestions, quite a lot of the time

		it’s if you see this do this or you know those kinds of things and sometimes you’re looking at how to keep them in the green light zone so that sort of when they are settled they call it the green light and then looking at the amber signs so the warning signs and the triggers erm and sort of looking at what has worked in the past and what the PBS says to do in those times and also looking at the reasons behind it” (Emma)
		“When you do your research and you do sit and watch, when you do listen er you in your own head you sort of get your reasonings for it, you could be completely wrong, you know you could be, I could sit there and say “yeah I believe that when that person does that when they’ve got er a really bad pain, they can’t tell me that but I believe that because when they are wanting a biscuit their behaviour is this” so d’you know what I mean? It’s a lot of breaking it down and working out” (Mary)
2. Using PBS as a Health Care Assistant	2.1 The Involvement of HCAs in the Development and Implementation of PBS Plans	*“I think we kind of need to find a way to make that input better so that everybody gets the chance to have that input, because sometimes it will be a sit down discussion with people who are on that shift that day you know, which is great if there’s the opportunity to sit down with a couple of people but that also needs to be done throughout the week or throughout the two weeks so you’re kind of catching everybody as much as you can rather than it just being, oh right I sat down with this team and they think this so this is what we’re going to do, because that’s not a very sort of large sort of research group so to say, it’s not a very large population to go off of, erm so I think I know PBS sort of have to be put in place as quick as we can erm I also think that we make sure that everybody is getting that input and their say, be it an email you know give me, if an email was sent out where, we’re putting a PBS together for this person can you all email me what you think, what are your suggestions?” (Emma)*
		“erm not very, erm I think at the moment maybe here because we haven’t got the patients in or we’ve got existing patients erm but I think as a team not just me, I think as a team we all like to be included because we all work with everybody and like I said earlier we all have different ideas,

		different values, different views, erm but no I think we could be more included” (Mary)
		“I think they’re a useful guidance and it just gives you that, like I say, you can’t get that PBS and say “right he’s started with that let’s do this” do you know what I mean? It gives you ideas of what to sort of do, oh right he’s got to that point so we’re going to have to do this, you have to work with the situation more than that, that gives you the, the history, that gives you the, the sort of general understanding of behaviour and how and how, but that could be completely different, you know, and different things work on different days” (Mary)
	2.2 PBS Intertwined in HCA Work	*“I’d say it affects it positively because it does give you such a sort of foundation to sort of work from. You know really the like roots of everything you should and shouldn’t be doing because really from the PBS you know pretty much everything about someone’s behaviour or the functions of it” (Dave)*
		“Like I said empathy, understanding, knowing the right approach [pause] identifying you know when, oh right we are moving from green to amber if we’re not careful we are going to be going to red so let’s move, let’s change the environment, change the dynamic, withdraw, yeah so you better understand that process I think so you can make the right intervention or just come away and erm just calm the situation down so it’s just yeah, it gave a structure to yeah what would see like a common sense approach, it sort of is erm but it gives you a structure and a way of thinking” (Roger)
	2.3 Successes and Positive Challenges	*“Erm I think personally speaking like with working with our client group, what I’ve observed from the PBS is that if we stick to the PBS the incidences become less and less and less and less” (Jenny)*
	2.4 The Challenges of Working with BTC and Risk	*“Erm, so yeah I’d say the biggest sort of barriers are normally sort of safety, you can’t just stick around just to be trying out all these things you need to be just getting away because it’s dangerous erm yeah.” (Dave)*
3. Relationships	3.1 A Consistent, Cohesive and Persistent MDT Approach	*“You know I think if a person feels safe around you then you’re going to have more of a relationship with them, you know I think if you read the*

		PBS plan and go oh no I don’t think that’s right or I’m going to ignore that or erm you sort of react differently you know that, for your relationship with that person, it might not be as good because they expect a certain reaction to a certain behaviour, you know if someone comes in and does things differently you can risk sort of that being quite detrimental to that relationship” (Emma)
		“Well I suppose it makes everybody consistent, we work consistently and I think that’s what you need in this type of role, because if everybody’s working in a different way it doesn’t always work” (Yeslel)
		“So it’s knowing what’s the best to do for that person erm yeah, so that’s the biggest sort of hurdles that we’ve gone through, trying to get as much information on people, how best to work with somebody, what resources we need, what support we need from the MDT [multidisciplinary team], you know it’s sort of a collaborative approach, that’s been the biggest challenge for me because when you somebody that’s really distressed you just want to help them and it’s knowing what level of help we need to input or implement yeah” (Jenny)
		“Getting consistency as a staff team if we were getting told things and someone else was being told another thing you know it was just building up that approach erm you know it’s about team work really and if someone goes rogue and goes solo it just causes all sorts of problems cos if you’ve built up a trust and a way of working and somebody just broadsides you you’ve got to start again” (Roger)
	3.2 Therapeutic Relationships	*“I think it is just relationships, you need to be able to have a rapport and to be able to appreciate and respect that patient on a level, you know we are equal to them. They have moments in their life where they get distressed, angry, you know they are no different to the rest of us, and it’s just appreciating that it could be exacerbated by a simple thing, it could be that someone’s not understood their need” (Jenny)*

		“Like I’ll do an interest checklist with them so they’ll give me a list of things they like and don’t like, so I’m not going to offer anything that’s going to be upsetting to them, they might have had previous trauma, there might be PTSD, there might be something associated with that” (Jenny)
	3.3 Patients Should be Involved More but There are Barriers	*“Again patient involvement you know there needs to be more involvement with the patients where possible, sitting down and having those conversations with them and working out how we can best support them” (Emma)*
		“I think communicating with the patient as well if that’s something that you can do if that’s- dependent on communicating in a way that the patient understands and can communicate back with you to kind of figure out why that behaviour has occurred so sort of like a debrief for the patient erm you know if there’s been an incident once people are back to their baseline behaviour so that sort of normal or we say “normal” as what is normal for that person their sort of baseline mood sort of general presentation when they’re back to that, you’d maybe look at sitting down with that person and saying, we’ve noticed this, is this something- was this something that caused this in your eyes that you noticed it might have been through this, do you agree? So you can talk to people about what maybe causes that behaviour as well” (Emma)
		“No, I don’t recollect that there was although I’m sure the [PBS Coach] had a separate session with the individual but I think the one I particularly remember was the team that generally worked with the person, we just all sat and erm and just shared round the table you know what best practice is and what would work and what doesn’t work” (Roger)