Autonomy and its Role in the Development, Treatment and Management of Borderline Personality Disorder

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Word Count

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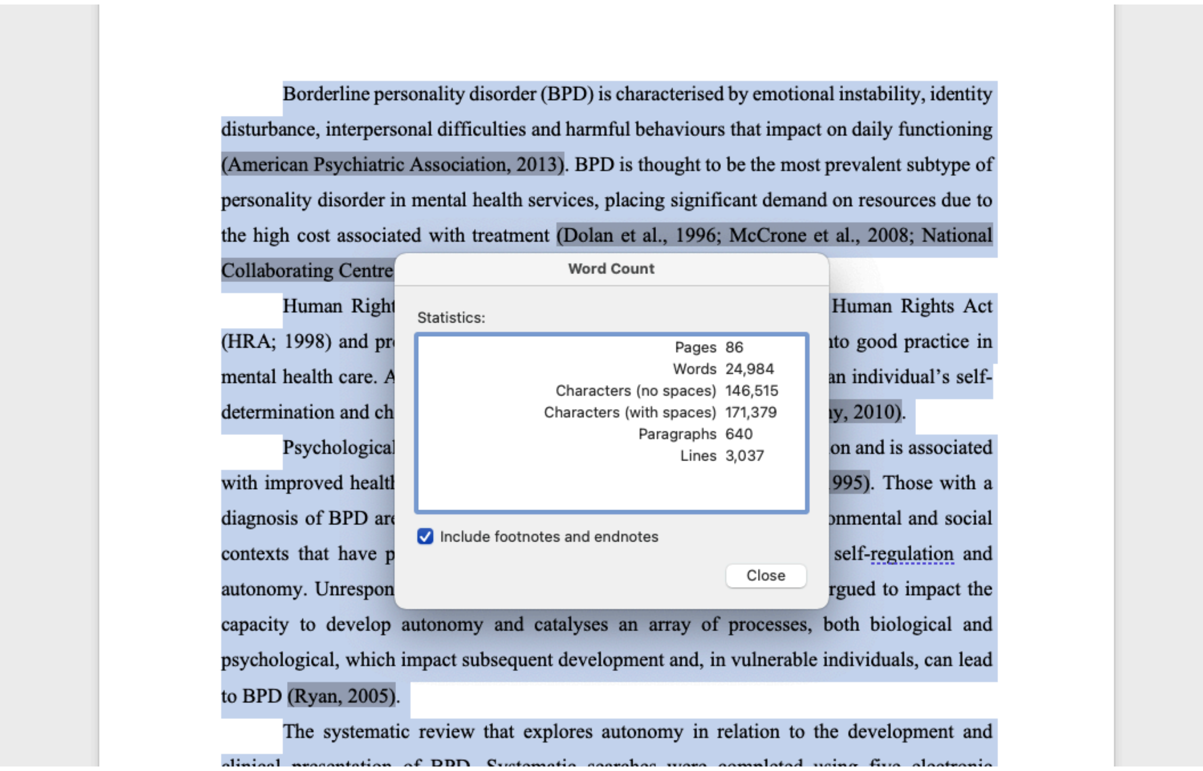

Borderline personality disorder (BPD) is characterised by emotional instability, identity disturbance, interpersonal difficulties and harmful behaviours that impact on daily functioning (American Psychiatric Association, 2013). BPD is thought to be the most prevalent subtype of personality disorder in mental health services, placing significant demand on resources due to the high cost associated with treatment (Dolan et al., 1996; McCrone et al., 2008; National Collaborating Centre

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The systematic review that explores autonomy in relation to the development and

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Introductory Chapter: Thesis Overview

Borderline personality disorder (BPD) is characterised by emotional instability, identity disturbance, interpersonal difficulties and harmful behaviours that impact on daily functioning (American Psychiatric Association, 2013). BPD is thought to be the most prevalent subtype of personality disorder in mental health services, placing significant demand on resources due to the high cost associated with treatment and extensive levels of support required (Dolan et al., 1996; McCrone et al., 2008; National Collaborating Centre for Mental Health, 2009; Rendu et al., 2002).

It is important to acknowledge the use of diagnostic categories throughout the thesis. The client group in which both the systematic review and empirical paper is based are reported to have a diagnosis of borderline personality disorder (BPD) according to the DSM-IV (American Psychiatric Association, 2013). Emotionally unstable personality disorder (EUPD) is diagnosed using the International Classification of Disease (ICD-11) (World Health Organization, 2018). Anecdotally it is noted that the two diagnostic entities are often used interchangeably. However, for the purposes of this thesis the term BPD is referred to.

Such diagnostic entities are contentious as they are considered unreliable (Allsopp et al., 2019; Carcone et al., 2015; Lucy Johnstone, 2018; Reich, 1989; Zimmerman, 1994) and are associated with negative attitudes and stigmatisation (Chartonas et al., 2017; Deans & Meocevic, 2006; Lewis & Appleby, 1988; Rogers & Dunne, 2011; Woollaston & Hixenbaugh, 2008). Experts by experience were consulted throughout the research process and participants were also provided opportunity to express their views on their diagnosis in both interview and feedback forums. Neither experts by experience or participants objected to the use of diagnostic terminology research purposes and reported they valued the opportunity to reflect on their experiences. Importantly, it was noted that the associated negative attitudes and perceived impact on treatment was felt to be harmful rather than the use of diagnostic terminology itself. Therefore, it was agreed that use of diagnostic terminology for the purposes of the current research was appropriate if it meant exploring ways to improve the experience and challenges the service user group faces.

Human Rights Based Approaches (HRBAs) are drawn from the Human Rights Act (HRA; 1998) and provide a framework for translating the Act articles into good practice in mental health care. Autonomy is a key feature of a HBRA and relates to an individual's self-determination and choice about what happens to them (Curtice & Exworthy, 2010).

Psychological experience of autonomy is said to assist self-regulation and is associated with improved health and wellbeing (Ryan & Deci, 2000; Ryan et al., 1995). Those with a diagnosis of BPD are understood to have been exposed to harmful environmental and social contexts that have prevented their ability to develop self-organisation, self-regulation and autonomy. Unresponsiveness, invalidation or abuse from care givers is argued to impact the capacity to develop autonomy and catalyses an array of processes, both biological and psychological, which impact subsequent development and, in vulnerable individuals, can lead to BPD (Ryan, 2005).

The systematic review explores autonomy in relation to the development and clinical presentation of BPD. Systematic searches were completed using four electronic databases and thirteen papers were included based on the predetermined criteria. Narrative synthesis enabled integration data from quantitative, qualitative, and mixed methods studies; quality was assessed using the Mixed Method Assessment Tool (MMAT) (Hong et al., 2019) (see Appendix 3). Factors associated with the development of autonomy included: parents and parenting style; attachment and lack of parental care; mothers with BPD. Factors that highlighted problems related to autonomy in the clinical presentation of BPD included: identity, connecting with others, coping styles; treatment and intervention.

The empirical paper was written in preparation for submission to The Journal of Mental Health (see Appendix 1). This paper utilised grounded theory methodology to explore service users experience of autonomy in a specialist community-based personality disorder service, and the experiences of mental health professionals providing treatment and intervention. A theoretical model was created from the findings that conceptualises 'relational autonomy'.

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Chapter 1: Systematic Review

The role of autonomy in the clinical presentation and development of borderline personality disorder: A systematic review

Rebecca Goodfellow

Abstract

The psychological experience of autonomy assists self-regulation and is associated with improved health and wellbeing. Those with a diagnosis of borderline personality disorder (BPD) are understood to have been exposed to harmful environmental and social contexts that have prevented their ability to develop self-organisation, self-regulation, and autonomy. Invalidation or abuse from care givers is argued to impact the capacity to develop autonomy and catalyses an array of processes, both biological and psychological, which impact subsequent development and, in vulnerable individuals, can lead to BPD. The aim of the current review is to systematically review the existing literature related to autonomy in the clinical presentation and development of BPD. Four electronic databases systematically searched for relevant studies. Based on inclusion criteria, a total of thirteen studies were included in the narrative synthesis. The diverse nature of autonomy in the clinical presentation and developmental factors associated with BPD was evident in the varied evidence base. Factors associated with the development of autonomy included: parents and parenting style; attachment and lack of parental care; mothers with BPD. Factors that highlighted problems related to autonomy in the clinical presentation of BPD included: identity, connecting with other, coping styles; treatment and intervention. Reduced sense of autonomy has implications for forming therapeutic relationships and how the clinical population accesses services. Further exploration is required to identify specific barriers to utilisation of mental health services formation of therapeutic alliances.

Introduction

Defining autonomy

Autonomy is said to refer to actions that are initiated and regulated by the self, a form of 'self-rule'. Autonomous behaviours are those that an individual willingly supports and engages in (Ryan, 2005), that have a quality of openness and flexibility (Shapiro, 1981). Self-determination theory (SDT) posits there are basic psychological needs concerning autonomy, competence, and relatedness, which are considered to be the interpersonal and cultural supports integral for self-organisation and integrity. Here, autonomy is defined as the capacity for self-endorsed action based on integrative and reflective awareness. Psychological experience of autonomy is said to assist self-regulation and is associated with improved health and wellbeing (Ryan & Deci, 2000; Ryan et al., 1995).

Autonomy is often considered to lie within the individual and is predominantly a Western concept. Individual autonomy emphasises independence, minimising the role of systems and connection to others that support decision-making. Interdependence is at the centre of relational autonomy, highlighting how reciprocal relationships enable someone to flourish and develop further capacity for self-determination (Dove et al., 2017).

Autonomy and Development

The capacity to develop autonomy is thought to be dependent upon opportunities for a young child to participate in relationships with caregivers that are attuned and sensitive to their needs and emotions (Bleiberg, 2004; Siegel, 1999). Autonomy and self-regulation are said to be integral to healthy development (Hartmann, 1958; Piaget, 1981; Werner, 1948) and can thus be thwarted by early relationships and controlling environments (Baumrind, 1971; Grolnick, 2003; Grusec & Goodnow, 1994; Ryan & Deci, 2000).

Autonomy support is any provision of a caregiver that strengthens the recipients' sense of self and their own capacity to manage and regulate their own internal experiences and external actions. Key aspects of autonomy support include: sharing, mirroring and reflecting the child's perspective and maximising their sense of authorship, choice and ability to develop awareness of internal locus of control (Ryan, 2005). Psychological theories relevant to the support for autonomy include attachment and development of mentalisation abilities, both highlight the importance of the caregiver being sensitive and response to the child's needs and mental states (Bretherton, 1987; Gergely & Watson 1996).

Borderline Personality Disorder

According to diagnostic criteria, borderline personality disorder (BPD) is characterised by affect instability, identity disturbance, interpersonal difficulties, impulsivity and harmful behaviours that impact on daily functioning (American Psychiatric Association, 2013; Loranger, 1999). Psychological theory emphasises the negative impact of environmental and developmental deprivation on a child's development and subsequent BPD symptomology. As such, BPD is thought to develop as the result of harmful social contexts, invalidating environments (where a child's emotional expressions and feelings are dismissed and considered incorrect) trauma and adverse childhood experiences (Linehan, 1993; Porter et al., 2020). Biosocial theory highlights the importance of a child's early experience in the development of BPD, particularly the impact of families and invalidating environments (Linehan, 1993). Psychodynamic theories highlight the important role of caregivers in the development of motivation and emotion regulation processes (Bradley & Westen, 2005).

The label and reliability of categorical diagnosis are highly contestable (Allsopp et al., 2019; Bentall, 2009; Lucy Johnstone, 2018). The BPD label has been criticised and is associated with negative attitudes from some mental health professionals, impacting negatively on care and treatment (Chartonas et al., 2017; Dickens, Lamont, et al., 2016; Rogers & Dunne, 2011). The diagnostic process has also been scrutinised. Semi structured interviews used to diagnose BPD have shown strong inter-rater reliability and questionable test-retest reliability, which has implications for the validity of personality disorder diagnoses (Reich, 1989; Zimmerman, 1994). However, a more recent review demonstrated strong support for the reliability of semi-structured diagnostic interviews for BPD (Carcone et al., 2015).

BPD and Autonomy

Those with a diagnosis of BPD are understood to have been exposed to harmful environmental and social contexts that have prevented their ability to develop self-organisation, self-regulation and autonomy. Unresponsiveness, invalidation or abuse from care givers is argued to impact the capacity to develop autonomy and catalyses an array of processes, both biological and psychological, which impact subsequent development and, in vulnerable individuals, can lead to BPD (Ryan, 2005). Decreased capacity for autonomy is said to be a key feature of BPD with some defining it as a 'disorder of autonomy', resulting from the disruption of basic and associated psychological needs (Ryan, 2005; Ryan et al., 1995).

Through a developmental perspective, how autonomy is understood varies across the lifespan in the context of changing regulatory capacities of individuals and the changing demands that individuals are required to regulate (Ryan & La Guardia, 2000). Beck et al. (1990) stated that BPD is characterised by a broad set of beliefs including both sociotropic (e.g. fear of abandonment) and autonomous (e.g. fear of being controlled, core sense of badness or unworthiness) themes. Among those who exhibit borderline features, Ryan & Shean (2007) found two distinguishable groups; autonomous and dependent subtypes. The autonomous type was characterised by problems of being overly assertive, lack of intimacy and keeping others at a distance. The dependent subtype was characterised by submissiveness, having little influence over others, difficulty conveying needs, obtrusiveness and low self-confidence. Linehan (1993) described those with BPD as fitting within one of two characteristic patterns of relating. These were referred to as 'butterfly-like' or "attached". 'Butterfly-like' individuals have difficulty forming attachments and tend to 'flutter' in and out of relationships. 'Attached' clients are described as tending to form quick and intense, dependent but turbulent relationships.

The aforementioned literature utilises 'autonomy' as the dominant phrase to encapsulate difficulties in self-determination and empowerment. However, there are philosophical similarities in 'agency' (Cummins, 2014) that may be relevant to BPD symptomology. For example, a defining feature of BPD is identity disturbance (American Psychiatric Association, 2013; Jørgensen, 2010; Kernberg, 1984; Loranger, 1999). Agency and identity disturbance may be linked when one considers the difficulties these individuals face in defining themselves as empowered and capable of exercising influence over their own personal circumstances (Bateman & Fonagy, 2006; Bradley & Westen, 2005; Fuchs, 2007; Jørgensen, 2010). Similar to autonomy, the development of a personal sense of agency has also been found to be related to positive psychological functioning (Adler, 2012).

Human Rights Based Approaches

Human Rights Based Approaches (HRBA) are drawn from the Human Rights Act (HRA; 1998) and provide a framework for translating the Act articles into good practice in mental health care (Curtice & Exworthy, 2010). The PANEL (Participation, Accountability, Non-discrimination, Empowerment and Legality) and FREDA (Fairness, Respect, Equality, Dignity and Autonomy) principles offer a structure for a HRBA (Curtice & Exworthy, 2010;

DoH & BIHR, 2008). Autonomy is a key feature and is included within the Mental Health Act (1983) Code of Practice and Mental Capacity Act (2005).

Public bodies have a positive obligation to promote rights (Department of Health and Social Care, 2021). However, according to the HRA, not all rights are absolute, and some rights can be limited. It is important to understand when and why rights are limited and how these decisions are made, as HRBAs and respecting rights can impact care and mental health (Mansell & Beadle-Brown, 2004). Those with a diagnosis of BPD are amongst those receiving care who may be more likely to have their human rights undermined given their difficulties in relation to autonomy and the challenging behaviours they may display.

Review aims

This review is set within an established literature examining autonomy and its contribution to the development of borderline personality disorder, and its enduring characteristics. Given that autonomy is a key feature of BPD (Ryan, 2005), a strong literature base relating the two concepts is foreseeable. However, the specific role of autonomy in symptomology of and distress caused by BPD is less clear and requires investigation. Therefore, using narrative synthesis, this systematic review aims to answer the question, ‘what is the role of autonomy in the clinical presentation and development of borderline personality disorder?’.

Method

Search strategy

Initial scoping searches were used to identify whether the current review question had already been examined elsewhere. Scoping searches and main searches were undertaken using the Healthcare Databases Advanced Search (HDAS) interface, developed by the National Institute of Clinical Excellence (NICE). These preparatory scoping literature searches revealed that there were several book chapters and theoretical papers in relation to BPD and autonomy. However, it was decided to exclude this type of literature due to difficulties in relation to quality assessment and potential lack of rigour in their peer review process.

Using the HDAS interface, the PsycINFO, PubMed, CINAHL and Medline databases were searched using and combining the terms ‘autonomy’ and ‘systematic review’. There were several hundred entries returned in these searches, but no reviews were found that addressed the current review question or that specifically related autonomy to borderline personality disorder.

Initial scoping searches of the literature indicated that autonomy was often referred to and described using broader related concepts. Therefore, in order not to discount this literature it was decided that ‘autonomy’ would be used in combination with the following related search terms: self-determination; agency; decision-making; freedom.

A search of the PROSPERO register for ‘autonomy’ in the title field revealed that there were seventeen reviews ongoing, but these were not related to borderline or emotionally unstable personality disorder. A further search of the register and ongoing review titles using the term ‘borderline personality disorder’ returned 89 entries and a search using the term ‘emotionally unstable personality disorder’ returned two entries. Each entry title was read to ensure that a review with the same or similar aims was not registered. None of the entries were relevant to the current review. A proposal for the current review was submitted and registered on the PROSPERO website (ID: CRD42020199468) (see Appendix 2).

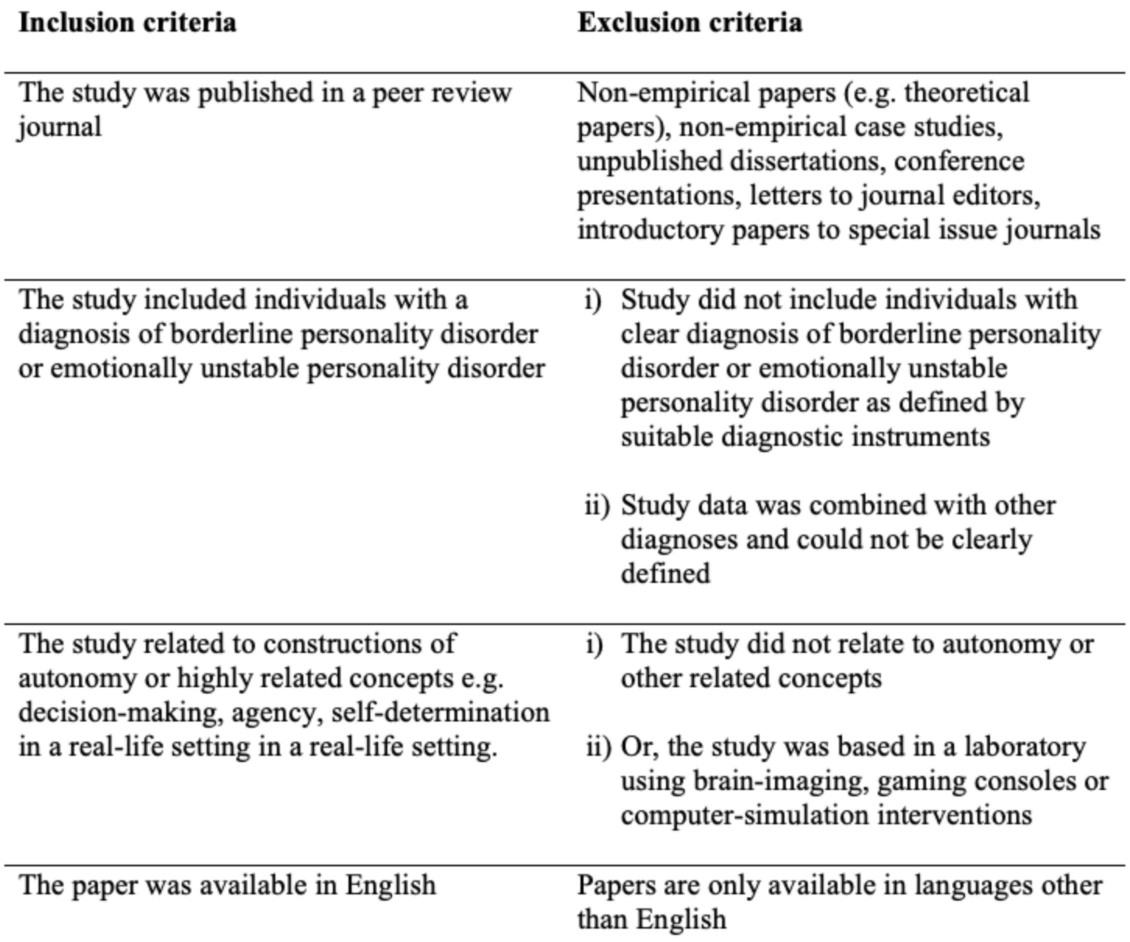
In consultation with the research team, and due to time constraints, complex nature of the topic and anticipated difficulties assessing quality, unpublished or ‘grey’ literature was not included in the current review.

Study selection

To capture concepts related to autonomy the following terms were used: ‘autonom*’ OR ‘decision-making’ OR ‘self-determin*’ OR ‘freedom’ OR ‘agency’. This search term was combined with ‘borderline personality’ OR ‘BPD’ OR ‘emotionally unstable personality’ OR ‘EUPD’. Four electronic databases were searched in November 2021. The databases used were CINAHL, Medline, PsycINFO and Pubmed. These databases were selected following consultation with a librarian in relation to the review question and appropriate sources that would be compatible with psychologically-informed literature. There were no limits set in relation to publication date. However, due to practical resource limitations, only papers published in English were included.

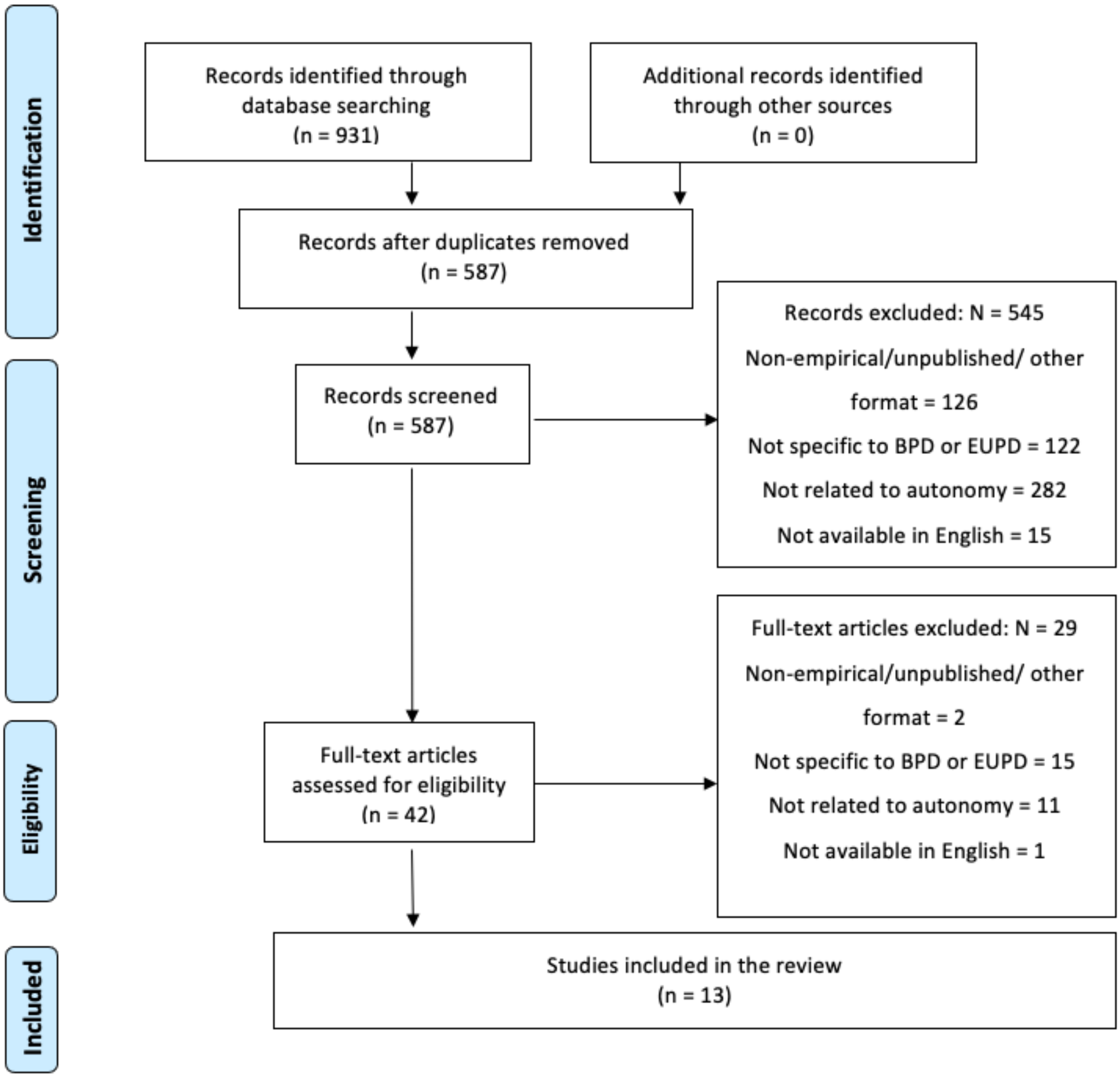
The main search returned 931 papers. Duplicates were removed using HDAS, leaving 587 papers. All citations were then extracted and organised using Mendeley^{TM} reference management software. These citations were screened using their title and abstract based the inclusion and exclusion criteria (see Table 1). Ten percent were assessed blindly by the research supervisors to further ensure agreement rigour to the screening process. Where suitability for inclusion was unclear, based on the title and abstract, the author referred to the full text version of the study. Forty-two papers were reviewed in full. Following this in-depth screening process, 13 studies were considered to meet the inclusion criteria for the current review. The PRISMA flow chart below illustrates the screening process (see Figure 1).

Table 1. Review studies inclusion and exclusion criteria.



Inclusion criteria	**Exclusion criteria**
The study was published in a peer review journal	Non-empirical papers (e.g. theoretical papers), non-empirical case studies, unpublished dissertations, conference presentations, letters to journal editors, introductory papers to special issue journals
The study included individuals with a diagnosis of borderline personality disorder or emotionally unstable personality disorder	i) Study did not include individuals with clear diagnosis of borderline personality disorder or emotionally unstable personality disorder as defined by suitable diagnostic instruments ii) Study data was combined with other diagnoses and could not be clearly defined
The study related to constructions of autonomy or highly related concepts e.g. decision-making, agency, self-determination in a real-life setting in a real-life setting.	i) The study did not relate to autonomy or other related concepts ii) Or, the study was based in a laboratory using brain-imaging, gaming consoles or computer-simulation interventions
The paper was available in English	Papers are only available in languages other than English

Figure 1. PRISMA Flow Diagram.



Data extraction and quality assessment

Each study was quality assessed using the Mixed Method Assessment Tool (MMAT; Appendix 3) (Hong et al., 2019) (see Table 2). A single quality appraisal tool was selected, rather than using separate and distinct quality assessment tools for the heterogenous studies included in the current review. The MMAT (Hong et al., 2019) was chosen for its efficiency and ability to address the critical appraisal of studies which have a variety of research designs and methods. The MMAT has two screening questions applied to all included studies followed by specific questions for five categories of empirical study. Categories of empirical study are qualitative studies, randomised control trials, non-randomised studies, quantitative descriptive studies and mixed method studies. Each study was reviewed against the relevant criteria. Reflections and findings of quality appraisal are presented in the review findings.

Method of Synthesis

To enable accurate and systematic comparison, key features and findings from included studies were extracted (see Appendix 4). Definitions and theory related to autonomy present in empirical papers were incorporated into the synthesis of the current review. Extracted information include study design, measures used, key findings, clinical and treatment implications and definitions and theories related to autonomy.

Data were analysed in detail to explore themes and relationships between included studies using a narrative approach. Such an approach to synthesis of the extracted data was undertaken to allow incorporation of data from a range of methodologies (Popay et al., 2006). Recurring, relevant and pertinent findings from each study were clustered into meaningful categories that were considered to capture important aspects of the data that highlight features of autonomy in the client group.

Table 2. Quality assessment using the Mixed Method Assessment Tool (MMAT).

	Screen		**Qualitative**					**Randomised**					**Quantitative non-randomised**					**Quantitative descriptive**					**Mixed Methods**				
Study	Are there clear research questions?	Do the collected data allow to address the research questions?	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Is randomization appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to the intervention provided?	Did the participants adhere to the assigned intervention?	Are the participants representative of the target population?	Are measurements appropriate regarding both the outcome and	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or exposure occurred) as intended?	Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Adler et al. (2012)	y	y											y	y	y	y	y										
Barone (2003)	y	y											y	y	y	y	y										

Benjamin & Wonderlich (1994)	y	y											y	y	y	y	y										
Frankel-Waldheter et al. (2015)	y	y											y	y	y	y	y										
Koivisto et al. (2021)	y	y																					y	y	y	y	y
Kramer (2014)	y	y											y	y	y	y	y										
Kramer (2017)	y	y						Can't tell	y	y	Can't tell	y															
Kverme et al. (2019)	y	y	y	y	y	y	y																				
Laporte & Guttman (2007)	y	y											y	y	y	y	y										
Leihener et al. (2003)	y	y																y	y	y	Can't tell	y					

Lind & Thomsen et al. (2019)	y	y	y	y	Can't tell	y	y
Lind, & Jørgensen, et al. (2019)	y	y	y	y	y	y	y
Macfie et al. (2017)	y	y	y	y	y	y	y

Results

Overview of included papers

Thirteen articles published between 1994 and 2021 met the inclusion criteria. A summary of included studies is provided in Table 3. Studies varied in their definitions of autonomy and its application to participant samples. Table 3 summarises each article's aims, generalised view of autonomy and theories used that relate to autonomy. Eleven quantitative studies were included in the review: one randomised control trial, nine non-randomised studies, one descriptive study. One study used qualitative methodology and one study utilised mixed methods.

Table 3. Study characteristics.

Study	**Sample and context**	**Measures to investigation**	**Key findings**	**Definitions/theory/concepts related to autonomy**	**Clinical implications**
Adler et al. (2012)	BPD = 20 Matched comparisons= 20 United States	Structured Interview for DSM-IV Personality **(SIDP-IV)**. Multisource Assessment of Personality Pathology **(MAPP)**. Life story interviews Beck Depression Inventory **(BDI-II)**. Dyadic Adjustment Scale **(DAS-4)**. RAND-36 Health Status Inventory **(HSI).**	BPD: Narrative identity significantly lower in agency, communion fulfilment. Agency strongly associated with mental health outcomes 6- and 12 months follow-up.	- Narrative identity disruption in BPD and agency (A. Bateman & Fonagy, 2006; Bradley & Westen, 2005; Fuchs, 2007). - Immediate impulsive action: BPD individuals unable to view themselves as the initiator of the act, under control of external forces (Bradley & Westen, 2005). - Agency related to positive psychological functioning (Adler, 2012).	BPD is related to identity disturbance. Diminished agency, communion fulfilment, and coherence relevant in context of DBT, MBT and psychodynamic psychotherapy.
Barone (2003)	BPD=40 Non-clinical sample=40 Italy	Axis I Structured Clinical Interview for DSM-IV **(SCID-I)**. Axis II Structured Clinical Interview for DSM-IV **(SCID-II)**. Adult Attachment Interview **(AAI)**.	BPD attachments categorised as: 7% free/autonomous, 20%, dismissing, 23% entangled/preoccupied, 50% unresolved with traumatic experiences.	- Autonomous-secure attachment patterns correspond with adaptive styles of cognitive processing and emotional regulation. Insecure and disorganised attachment patterns correspond with cognitive distortions of information processing linked to emotional and interpersonal dysregulation (Carlson & Sroufe, 1995).	Central to BPD development: Difficult developmental relational experiences, increased maximisation of attachment strategies, dysfunctional patterns of attachment and unresolved trauma.
Benjamin & Wonderlich (1994)	BPD=31 Depression=39 Bipolar=13 United States	Interpersonal Adjective Scales-Revised **(IAS-R)**. Structural Analysis of Social Behaviour Rating Scales **(SASB)**.	BPD: Viewed relationships with mother as hostile and highly autonomous. Showed less normative self-control. Bipolar: Viewed relationships as non-hostile and interdependent.	- Structural Analysis of Social Behaviour (SASB) circumplex model of interpersonal relationships (Benjamin, 1974). Autonomy described as opposite of dominance (Schaefer, 1965).	Support for models of BPD to include interpersonal factors. BPD and bipolar individuals different and distinct at level of interpersonal perceptions and how they view relationships with others. BPD view as hostile and autonomous. Bipolar view as non-hostile and interdependent.

Frankel-Waldheter et al. (2015)	BPD mothers and adolescent children (aged 14-17)=28 Matched comparisons= 28 United States	Peabody Picture Vocabulary Test **(PPVT)**. Axis I Structured Clinical Interview for DSM-IV **(SCID-I)**. Axis II Structured Clinical Interview for DSM-IV **(SCID-II)**. Personality Assessment Inventory. Teacher Report Form **(TRF)**. Problem-solving inventory. Autonomy and Relatedness Coding System Manual (v2.14).	BPD mothers more likely to inhibit autonomy but equally likely to promote autonomy with their adolescents. Borderline features mediated relationship between promotion and inhibition of autonomy and relatedness resulting in adolescent BPD features and internalizing and externalizing symptoms.	- Autonomy as self-governance (Turner et al., 1993). - Self-determination theory: three basic human need: autonomy, relatedness, and competence (Deci & Ryan, 1980). - BPD develops from difficulties with autonomy and relatedness (Ryan et al., 2006). - Mothers past and current unmet needs impact ability to parent and support autonomy and relatedness (Macfie et al., 2008). - Object relations theory: caregiver feels threatened by the child's seeking autonomy and withdraws nurturance (Mahler et al., 1975). - Autonomy and relatedness are opposing and increase likelihood of BPD (Ryan, 2005; Ryan et al., 2006). (Ryan et al., 2006; Ryan, 2005).	Highlights 'at risk' groups and precursors to development of BPD symptomology. Desire for both independent and close relationships (autonomy and relatedness) important issue across the life span.
Koivisto et al. (2021)	BPD=8 Finland	In-depth interviews. Borderline Personality Disorder Severity Index-IV interview **(BPDSI-IV)**.	Four participants showed clinical recovery, two participants showed reliable change. Content analysis revealed three themes: 1) Improved ability to observe and understand mental events in oneself and others; 2) decreased disconnection from emotions and emergence of new, adaptive emotional reactions and decrease in maladaptive ones; 3) a new, more adaptive experience of self and agency. Helpful treatment factors: Learning and normalising.	- Vehicles for increased agency: Mentalisation and improved meta-cognitive abilities result in improved sense of self and self-compassion. - Normalisation of BPD symptomology promotes agency. Helps individuals to no longer view themselves as flawed and take action in recovery.	Learning about BPD supports making sense of and organising experiences. Psycho-education helps initiate cognitive-emotional processing. Long-term psycho-educational group therapy enhances mentalisation, meta-cognitive functioning and promotes self-integration.

			Treatment-related obstacles: Inflexibility and aggression in group.		
Kramer (2014)	BPD=25 Bipolar=25 Control group=25 Switzerland	Structured Clinical Interview for DSM-IV **(SCID-II)**. Coping Action Patterns Rating Scale **(CAPRS)**. Outcome Questionnaire-45.2 **(OQ-45)**.	Differences between BPD individuals and control group: competence, resources, and autonomy. Coping processes linked to general symptomology and BPD specific symptomology. Autonomy only coping domain presenting a BPD-specific lack of skills, compared with bipolar individuals.	Coping Action Patterns (Perry et al., 2005) encompasses two categories: 1) Coping with stress conceived as a challenge (adaptive coping); 2) Coping with stress conceived as a threat (non-adaptive coping). Each coping category is broken down into domains and action levels: - Challenge domain: Competence (problem solving and information seeking); resources (self-reliance and support seeking); autonomy (accommodation and negotiation). - Threat domain: Competence (helplessness and escape), resources (delegation and isolation), autonomy (submission and opposition).	Important for clinicians to assess micro-process level in-session coping processes in BPD individuals, with specific attention to lack of skills in autonomy domain.
Kramer (2017)	BPD= 31 Switzerland	- Outcome Questionnaire-45.2 (OQ-45) - Borderline Symptom List (BSL-23) - Interviews - Coping Action Patterns Rating Scales (CAP)	Increase in coping functioning in patients who underwent the DBT skills training. Increases in relatedness coping where the stress is appraised as challenge. Decreases in autonomy coping where the stress is appraised as threat.	- Coping action patterns (as above; Perry et al., 2005). - BPD individuals use of submission and opposition in autonomy coping strategies where stress is perceived as a threat: Stress perceived as others' actions as crossing a boundary and a force which impacting one's identity and sense of agency (Skinner et al., 2003).	Positive effect of DBT on coping in BPD. Important for therapists to comprehensively identify patients' coping styles and capacities.
Kverme et al. (2019)	BPD=12 Norway	In-depth interviews	Main theme: Moving towards connectedness. Subthemes: Learning to hold one’s own; needing honesty and genuine mutuality; daring to belong; making room for recovery. Support for autonomy key factor in therapy. Process of change	- Safety, social relationships and autonomy important for individual recovery (Shepherd et al., 2016). - Three phases of recovery: Attachment and dependence on a therapist, working together, moving autonomously on “into the world.” (Johansen et al., 2017). - Agency and autonomy healing phenomena (Bjornestad et al., 2017; Hansen et al., 2018; Moltu et al., 2017).	Continued training and education of mental health professionals and staff to develop more humanistic approaches that recognise the trauma people with BPD.

			related to the theme "learning to hold one’s own". Agency related to believing that change could come through action and changing old habits.		
Laporte & Guttman (2007)	BPD= 35 Anorexia nervosa= 34 Normative comparisons= 33 Canada	Revised Retrospective Diagnostic Interview for Borderline **(DIB-R)**. Eating Attitudes Test. Structured Clinical Interview for DSM-III-R **(SCID-III)**. Borderline Syndrome Index **(BSI)**. Symptom Checklist-90-R. Parental Bonding Instrument **(PBI)**.	BPD individuals reported significantly more maternal control of their psychological autonomy, than control group.	Three important to aspects in bonding between parent and child: 1) parental care; 2) parental protectiveness or denial of psychological autonomy; 3) authoritarianism or denial of behavioural freedom (Parker et al., 1979).	Early preventive interventions to target lack of care from parents. Interventions should target unempathetic and abusive treatments of a child, who later develops BPD.
Leihener et al. (2003)	BPD=95 Germany	Structured Clinical Interview for DSM-IV Axis II Disorders **(SCID-II)**. Inventory of Interpersonal Problems: brief version **(IIP-D)**.	BPD individuals classified into two subtypes based on self-reports of interpersonal behaviour. 1) Autonomous type: aloof, cold, difficult to feel close to others and show affection, not complaisant or submissive, too concerned with limiting intimacy. 2) Dependant type: autocratic, dominant, too little influence and control of others.	Treatment-seeking individuals with BPD described as "attached" (form quick and intense relationships) or "butterfly-like" (difficulty attaching and flutter out of therapy and relationships) (Linehan, 1993).	Heterogenous nature of interpersonal problems present in BPD. Important to focus on interpersonal difficulties in treatment. May improve therapy compliance and therapeutic alliance if able to identify autonomous-type BPD.
(Lind, Thomsen, et al., 2019)	BPD=30 Matched comparisons= 30 Denmark	Structured Clinical Interview for DSM-IV **(SCID-II)**. Life story interview (self and parents'). Self-Concept Identity Measure **(SCIM)**. Toronto Alexithymia Scale **(TAS-20)**.	BPD patients described their personal and their parents’ life stories more negatively and with fewer themes of agency and communion fulfilment, compared to normative control group. BPD patients displayed less complexity and more self-	- Agency associated with autonomy and empowerment of the individual (McAdams, 2001). - High degree of agency associated with better psychological functioning (Adler, 2012; McAdams et al., 1996).	Patients’ storied understanding of themselves and others are problematic and should be used to better understand BPD. Negative life stories may contribute to maintenance of BPD symptoms and become

		Empathy Quotient **(EQ)**. Mayer-Salovey-Caruso Emotional Intelligence Test v20 **(MSCEIT)**. Beck Depression Inventory **(BDI-II)**.	other confusion about their parents' stories.		self-fulfilling prophecies.
(Lind, Jørgensen, et al., 2019)	BPD=23 Matched controls=23 Denmark (follow up study from above)	Structured Clinical Interview for DSM-IV **(SCID-II)**. Life story interview (self and parents'). Beck Depression Inventory **(BDI-II)**.	Following 12 months of psychotherapy, BPD patients' personal life stories increased significantly in agency from baseline to follow-up compared with the control group.	- Positive and coherent life stories high in themes of agency and communion associated with better well-being (Adler, 2012). - Autonomy support and agency strengthens sense of self, mastery and emotional adjustment (Ryan, 2005).	Development of agency through the reconstruction of personal life stories crucial mechanism in psychotherapy with BPD patients.
Macfie et al. (2017)	BPD mothers and their children (ages 4-7)=36 Normative comparison group=34. United States	Structured Clinical Interview for DSM-IV Axis I Disorders **(SCID-I)**. Structured Clinical Interview for DSM-IV Axis II Disorders **(SCID-II)**. Personality Assessment Inventory **(PAI)**. Qualitative Ratings of Parent/Child Interaction.	BPD mothers less likely to be sensitive and provide autonomy support to their child. More likely to be hostile and display fearful/disoriented behaviour and higher levels of parent-child role reversal. Correlations between mother's borderline features and affective instability, identity disturbance, negative relationships, problems with sensitivity and autonomy support, hostility and role reversal.	Mothers with BPD are less likely to show autonomy support and more likely to exhibit fearful/disoriented behaviour than normative comparisons (Hobson et al., 2009; Newman et al., 2007).	Implications for child development and preventative interventions. Less autonomy support and sensitivity, and higher hostility from mothers with BPD may continue to adolescence and increase the risk of offspring developing BPD.

Quality appraisal

The quality of all studies was assessed using the Mixed Method Assessment Tool (MMAT) (Hong et al., 2019). No studies were excluded from the review based on quality and overall, all included studies were considered to be of high quality. Due to the high quality, all studies were considered to contribute a similar weighting to the review. However, there are some aspects of study quality that are outlined in the following paragraphs.

All studies provided adequate information in relation to recruitment and demographics of included participants. However, the randomised control trial did not appear to provide adequate information as to how participants were randomised to allocated conditions and the process by which investigators were 'blinded' to this process. Many studies utilised a cross-sectional design, with the exception of two longitudinal design studies (Leihener et al., 2003; Lind, Jørgensen, et al., 2019).

All quantitative studies provided acceptable information regarding the reliability and validity of their chosen measures and provided rationales for procedures and data analysis. There were two studies that were linked; Lind, & Jørgensen, et al. (2019) conducted a follow up study following twelve months of psychotherapy after a baseline study by Lind & Thomsen et al. (2019) who explored life stories of individuals with a diagnosis of BPD.

The authors of the mixed methods study (Koivisto et al., 2021) provided a reflexivity statement, however, for the qualitative study (Kverme et al., 2019), the author did not provide information on their position and influence within the research.

Studies were conducted in range of countries with seven studies conducted in European countries, four in the United States of America and one in Canada. There were no studies carried out in the United Kingdom. Participants were predominantly female, with three studies only including female participants (Kverme et al., 2019; Laporte & Guttman, 2007; Leihener et al., 2003). Studies with male and female participants controlled for gender in their analyses. Some studies used other clinical comparison groups, such as people with a diagnosis of bipolar (Benjamin & Wonderlich, 1994; Kramer, 2014) or anorexia (Laporte & Guttman, 2007).

Heterogeneity of Autonomy

One of the most notable findings from the current review is the diverse nature of how autonomy was defined and identified within the included studies. There were several approaches to exploring and investigating autonomy with the concept identified in different ways as to how it related to BPD, its diagnosis and treatment.

Autonomy was highlighted in attachment and parenting. Barone (2003) identified autonomous-secure attachment styles where only 7% of individuals with a BPD diagnosis were categorised as having a ‘free’ or ‘autonomous’ attachment style. The remainder of participants were classified as having insecure attachment styles.

Laporte & Guttman (2007) explored relational patterns with parents and found that those with a BPD diagnosis experienced their mothers as significantly more controlling of their psychological autonomy, compared to a control group. Frankel-Waldheter et al. (2015) and Macfie et al. (2017) investigated mothers who have a diagnosis of BPD. On problem-solving interactions, mothers were less likely to be sensitive and less likely to provide autonomy support to their child (Macfie et al., 2017) and also more likely to inhibit autonomy in adolescents (Frankel-Waldheter et al., 2015).

Autonomy was also investigated through interpersonal relationship styles using circumplex models. Benjamin & Wonderlich (1994) found that BPD participants were more likely to view their relationships with their mothers as highly autonomous and more hostile than the comparative clinical group. Leihener et al's. (2003) study of circumplex models identified BPD subtypes: an ‘autonomous’ and ‘dependent’ subtype.

Two studies utilised research on Dialectical Behaviour Therapy (DBT) to explore coping styles in those with a BPD diagnosis. When exploring adaptive and non-adaptive domains of stress-related coping styles, autonomous styles of coping were found to be problematic (Kramer, 2014) but DBT helped to overcome non-adaptive autonomous coping (Kramer, 2017).

In the overall recovery process, having and increasing a sense of autonomy and agency was highlighted as being important individuals with a diagnosis of BPD undergoing individual (Kverme et al., 2019) and group therapy (Koivisto et al., 2021). Life story work featured in three studies (Adler et al., 2012; Lind, Jørgensen, et al., 2019; Lind, Thomsen, et al., 2019). A lower sense of agency was a key issue for those with a diagnosis of BPD (Adler, 2012), which was also identified in life stories of their parents (Lind, Thomsen, et al., 2019) but this could be improved following psychotherapy (Lind, Jørgensen, et al., 2019).

Measurements of Autonomy

The qualitative study (Kverme et al., 2019) and mixed methods study (Koivisto et al., 2021) detailed use of semi-structured interviews to explore experience of BPD and recovery, which revealed themes related to autonomy and agency. Quantitative studies used a wide variety of measures including forms of investigation relevant to autonomy and assessments for diagnosis of other clinical and mood disorders. There were similarities and differences in the way studies collected data and measured autonomy with studies using pre-defined coding systems and self-report measures.

Life stories

Three studies utilised Life Story interviews (Adler et al., 2012; Lind, Jørgensen, et al., 2019; Lind, Thomsen, et al., 2019). Transcripts of the life story interviews were coded for narrative themes: including agency, communion, and communion fulfilment.

Attachment and Parenting

Four studies explored attachment and parenting styles. Barone (2003) used the Adult Attachment Interview (AAI) (George et al., 1996) to establish attachment patterns and categorises individuals with a BPD diagnosis into one of four categories: free/autonomous; dismissing; entangled; unresolved with traumatic experiences.

Laporte & Guttman (2007) used the Parental Bonding Instrument (PBI) (Parker et al., 1979) to investigate daughters' with a diagnosis of BPD experiences of maternal and paternal relationships, and overall experience of being parented. The measure has three factors measuring parental care, denial of psychological autonomy and denial of behavioural freedom.

Two studies (Frankel-Waldheter et al., 2015; Macfie et al., 2017) used observational paradigms where BPD mothers and their children engaged in problem-solving interaction tasks. Macfie et al. (2017) utilised Qualitative Ratings of Parent/Child Interaction (Cox, 1997) containing subscale measures of maternal sensitivity, maternal autonomy support, maternal hostility, maternal fearful/disoriented behaviour and mother-child role reversal. Frankel-Waldheter et al. (2015) used the Autonomy and Relatedness Coding System Manual Version 2.14 (Allen et al., 2003) with four composite domains: promotion of autonomy, promotion of relatedness, inhibition of autonomy and inhibition of relatedness.

Relationships

Two studies (Benjamin & Wonderlich, 1994; Leihener et al., 2003) used circumplex models of interpersonal behaviour with participants diagnosed with BPD. Leihener et al. (2003) used the self-report Inventory of Interpersonal Problems - brief version (IIP-D). BPD participants were classified into two distinct interpersonal categories: autonomous and dependent types. Benjamin & Wonderlich (1994) utilised the Interpersonal Adjective Scales-Revised (IAS-R) and Structural Analysis of Social Behaviour Rating Scales (SASB).

Coping styles

Two studies (Kramer, 2014, 2017) utilised ‘dynamic interviews’, developed from clinical practice of psychodynamic psychotherapy. Investigators used the Coping Action Patterns Rating Scale (CAPRS; Perry et al., 2005) to identify participant patterns of coping with stress from two predetermined domains: stress perceived as a challenge (adaptive coping) and stress perceived as a threat (non-adaptive coping). Each category contained three action levels: competence, resources and autonomy. Stress coping using strategies of autonomy in the challenge domain is defined as using accommodation and negotiation. In the threat domain, autonomy strategies for coping with stress were defined as submission and opposition.

BPD and Developmental Autonomy

Several studies highlighted factors that contributed to difficulties in BPD in the context of developmental aspects specific to autonomy. This included the role of attachment, parenting styles and mothers with a diagnosis of BPD.

Attachment and lack of parental care

In a study exploring attachment patterns, BPD participants were mostly categorised as having an insecure style (Barone, 2003). Only 7% were classified as having a free and autonomous style of attachment, compared to the non-clinical group where 62% were so classified. BPD participants were considered to have past experiences where mothers and fathers were considered rejecting and neglectful. When exploring parental bonding, regression analysis found that a general lack of care from both parents contributed to the diagnosis of BPD (Laporte & Guttman, 2007). These findings suggested that early experience and the quality of attachment patterns predict the degree of vulnerability to BPD symptomology. A secure attachment pattern, symbolic of support for autonomy, is said to correspond with adaptive styles of coping, cognitive processing, and emotional regulation. Whereas insecure and disorganised attachment patterns correspond to specific cognitive distortions in information processing and difficulties in emotional and interpersonal regulation, characteristics indicative of ‘personality disorder’ (Carlson & Sroufe, 1995).

Parents and parenting styles

Several studies explored aspects of parenting styles including participant perceptions of being parented and observational research of the mother-child interaction. Two studies found high levels of mother-child role reversal. One study included participants' with a diagnosis of BPD and their experiences of maternal care (Barone, 2003), while the other study was an investigation of mothers with a diagnosis of BPD caring for their child (Macfie et al., 2017). Barone (2003) found that, as well as BPD participants having significantly less free/autonomous attachment patterns, this group also experienced significantly more role reversal with their mothers, who did not hold the diagnosis. In Macfie et al's (2017) study, mothers with a diagnosis of BPD were less likely to be sensitive and provide autonomy support to their young child. These mothers were likely to be hostile and display fearful/disoriented behaviour and higher levels of parent-child role reversal. An example of role-reversal may include a child taking on a parental role, caring for their parent or acting more as their peer (Macfie et al., 2017). It is thought to be more likely to occur in BPD where they seek someone to soothe their distress and provide a feeling of secure attachment, a stable sense of self and emotional regulation. This may include their own child (Conklin & Westen, 2005) and has profound implications for their own developmental trajectory of BPD (Macfie et al., 2015).

When exploring parental bonding in participants with a diagnosis of BPD and anorexia compared to a control group (Laporte & Guttman, 2007), regression analysis found that a general lack of care from both parents (without a diagnosis of BPD) contributed to BPD diagnosis. Analysis of variance found that participants with BPD reported significantly more parental denial of autonomy compared to normative comparison groups and that parental denial of autonomy contributed to psychopathology in both clinical groups.

Benjamin & Wonderlich (1994) asked their adult participants to reflect on their early and current relationships with their parents and hospital staff. All clinical groups (participants with BPD, bipolar and depression) tended perceive others as, 1) clearly attacking or friendly, 2) controlling or autonomy/freedom giving, 3) submissive or autonomous. However, BPD participants viewed their relationships with their mothers (who did not hold a diagnosis of BPD) as highly autonomous and more hostile compared to the other participant groups. In this study, autonomy was considered opposite to being submissive and opposite to controlling. Authors concluded that BPD and individuals with a diagnosis of bipolar display potential fundamental differences in how they view relationships with others. For example, those with BPD diagnosis view relationships as hostile and autonomous while bipolar patients viewed relationships as non-hostile and interdependent. This provides evidence of distinction between bipolar and BPD in terms of their perceptions of interpersonal relationships, and this is thought to be support for psychosocial distinction (Benjamin & Wonderlich, 1994).

Mothers with diagnosis of BPD

The two studies that directly observed mothers with a diagnosis of BPD interacting with their children demonstrated potential risk factors in relation to their children developing symptoms of BPD (Frankel-Waldheter et al., 2015; Macfie et al., 2017). On problem-solving interaction tasks the mothers (with a diagnosis of BPD) were found to be more likely to inhibit autonomy (Frankel-Waldheter et al., 2015) or provide less support for autonomy (Macfie et al., 2017). Macfie et al. (2017) reported correlations between mothers self-reported borderline features and their sensitivity and autonomy support, hostility and role reversal. The more affective instability and identity disturbance in the mother's profile, the less sensitivity and autonomy support they displayed and the more hostility and fearful behaviour they displayed during interactions with their child.

Autonomy Related to Mood

Several studies explored links between autonomy (and agency), general mental health difficulties and symptomology relevant to BPD. Several of the participant samples throughout the studies reported comorbid clinical and mood disorders. Adler et al. (2012) found that the narrative identity of people with BPD was significantly lower in themes of agency which was also found to be strongly associated with mental health outcomes following completion of the study. At both 6- and 12-month time points, BPD participants' sense of agency was negatively correlated with reported symptoms of depression; meaning that the more depressive symptoms reported the lower their sense of agency and autonomy.

Lind & Thomsen et al. (2019) reported that the BPD samples had significantly more symptoms of depression, as measured by the Beck Depression Inventory (BDI-II). This was also reported at baseline and follow-up time points for BPD participants in Lind, & Jørgensen et al. (2019). In both studies, BPD participants had reported lower themes of agency in both their own and parents' life stories.

Autonomy and Identity

Four studies explored identity and highlighted difficulties in relation to agency and sense of self (Adler et al., 2012; Koivisto et al., 2021; Lind, Jørgensen, et al., 2019; Lind, Thomsen, et al., 2019). Koivisto et al. (2021) found a link between agency and improved sense of self. Participants reported inconsistent sense of oneself that was indicative of high self-criticism and low self-compassion. In turn, harsh self-criticism impacted the recovery process. Moving towards recovery, participants linked higher levels of agency with more consistent sense of self and greater self-care and self-compassion. The other three of these studies used life story work to explore narrative identity and discovered that those with a diagnosis of BPD had lower themes of agency (Adler et al., 2012; Lind, Jørgensen, et al., 2019; Lind, Thomsen, et al., 2019).

Connecting with Others

Autonomy featured in studies that focussed on concepts of relatedness and desire for social connection with others. Adler et al. (2012), Lind & Thomsen et al. (2019) and Lind, & Jørgensen, et al. (2019) demonstrated that life stories of BPD participants showed less emphasis in terms of themes of agency and communion fulfilment. Communion was defined as connection and intimacy of the protagonist, including friendships, romantic relationships and making social connections within the community or society. Communion fulfilment was whether or not the protagonist was able to achieve communion goals for social connection. Importantly, the studies found significantly fewer themes of communion fulfilment, not communion. This suggests that while BPD participants were motivated to build social connections with others, these desires where not realised. It may be that the disempowered protagonist had difficulty fulfilling their aspirations for connection with others due to issues of autonomy making it f difficult to carry out (Adler et al., 2012).

Frankel-Waldheter et al. (2015) defined relatedness as an emotionally close tie that is validating, engaging and involves curiosity about the needs and opinions of others. Autonomy was defined as self-governance and ability to act independently with confidence. Their findings suggest that both autonomy and relatedness underlie mother’s borderline features, finding that mothers were less likely to promote autonomy while being more likely to inhibit relatedness.

Connecting with others as a vehicle for increased autonomy was apparent in the main qualitative theme in Kverme et al.'s (2019) study. The more connected they felt within themselves and with others, the more they felt change was possible and the greater the sense of empowerment to make change.

Coping styles

When investigating adaptive and non-adaptive coping styles in BPD, bipolar participants and non-clinical controls, Kramer (2014) found that those with a BPD diagnosis had lower overall levels of adaptive coping, compared to the non-clinical control group. Predefined coping patterns included autonomy domains: autonomy appraised as a challenge and autonomy appraised as a threat. Coping adaptively was where the individual perceived stress as a challenge, reported a sense of mastery over a stressor perceived as controllable and was able to seek help in order to solve a problem. Alternatively, an individual may perceive stress as a threat where they feel overwhelmed and avoid overcoming a problem due to perceived lack of skill. In relation to autonomy, participants in the BPD group more frequently used unproductive autonomy coping processes (appraised stress as a threat) and less frequently used productive autonomy coping processes (appraised stress as a challenge) compared to healthy controls. Highlighting relationships between domains of autonomy coping and intensity of BPD symptoms, correlational analysis revealed that the more BPD symptoms reported related to being less likely to adopt autonomous coping as a challenge and more likely to adopt autonomous coping as a threat.

Treatment and Intervention

Three studies explored therapeutic interventions for BPD highlighting the saliency of autonomy and agency in therapeutic interventions. For example, a sense of agency, reflected in life stories, was found to increase after 12 months of receiving psychoanalysis or mentalisation-based therapy (MBT) (Lind, Jørgensen, et al., 2019). Kramer (2017) found that individuals with a BPD diagnosis who underwent a DBT skills training programme, in addition to treatment as usual (psychotherapy) showed specific decreases in unproductive coping styles.

Koivisto et al. (2021) found that after 40 sessions of CBT group therapy, individuals with a diagnosis of BPD who were found to have reached a period of recovery reported an increase in agency. An important aspect of recovery in this study was normalisation and learning of other’s experiences.

Increasing autonomy was also found to be important in the therapeutic and recovery journey for people with a diagnosis of BPD. Participants in the Kverme et al. (2019) reported on the importance of having therapists who clearly believed in their clients’ ability to change. In turn, participants began to embrace this belief. However, some participants reported they did not experience the same encouragement to learn to help themselves. These participants reported waiting to be changed by others and relying on others was important in their recovery. Experiencing a sense of ownership in their recovery journey was pivotal. For therapy to be of value, it appeared that relational specific aspects in the therapeutic alliance and context were important. This included honest mutuality and support for autonomy.

Discussion

The systematic review analysed the academic literature related to the role that autonomy plays in the clinical presentation and development of borderline personality disorder. Autonomy is a key feature of BPD (Ryan, 2005), resulting in a strong pre-existing literature base. Despite the pre-existing literature base, the specific role of autonomy within the symptomology of BPD, how it relates to experienced distress, the clinical presentation and its development was unclear. From initial scoping searches, it was clear that the literature was varied and there had been no previous systematic literature review conducted. Other previous systematic reviews focused on autonomy appear to have concentrated on alternative areas such as end of life care (Gómez-Vírseda et al., 2019) and those living with dementia (Boumans et al., 2019).

Thirteen articles published between 1994 and 2021 were included in the review. The most notable finding from the review was the diverse nature of autonomy in research with individuals with a diagnosis of BPD. Studies differed in their aims, theoretical approaches, methodological design, and utilisation of observational and psychometric measures. This resulted in a complexity when comparing studies and synthesising findings. Such complexity and heterogeneity of the included studies could be considered to parallel the diverse and complex nature of BPD symptomology and to highlight the inter-relationship between factors relevant to its development.

In relation to the role of autonomy in the clinical presentation of BPD, several studies linked autonomy to mental health presentation and symptoms. Autonomy has been found to be important in 'healthy' development (Baumrind, 1971; Grolnick, 2003; Grusec & Goodnow, 1994; Ryan & Deci, 2000) and psychological functioning (Adler, 2012). In the current review, life story work identified attenuated sense of agency in those with a diagnosis of BPD and this was linked to depressive symptoms and mental health outcomes (Lind, Jørgensen, et al., 2019; Lind, Thomsen, et al., 2019). Coping styles were important with autonomous coping being a particular difficulty, as identified by Kramer (2014). These findings highlight that those with a diagnosis of BPD may view themselves as less empowered and agentic and have fewer adaptive coping styles and that it is important to develop agency through a therapeutic relationship and throughout the recovery journey (Kverme et al., 2019). Therefore, autonomy has been identified as a specific difficulty in BPD but also instrumental in treatment gains. This further highlights the importance of healthy psychological functioning and potential ways to nurture this throughout recovery and therapeutic alliances.

The review findings also highlight the importance of autonomy in the context of attachment, parenting and healthy psychological functioning (Barone, 2003; Benjamin & Wonderlich, 1994; Frankel-Waldheter et al., 2015; Laporte & Guttman, 2007; Macfie et al., 2017). Attachment experiences where a child does not have a caregiver who responds in a way that fosters the support for autonomy and the development of adaptive self-soothing strategies may negatively impact a child's ability to develop own self-soothing, ability to self-regulate and develop a stable sense of self (Bowlby, 1980; Carlson & Sroufe, 1995; Fonagy et al., 2010). Such maladaptive methods of self-soothing, product of negative attachment experiences and support for autonomy are considered characteristic of BPD (Bowlby, 1980; Fonagy et al., 2010; Ryan, 2005). A secure attachment pattern, symbolic of support for autonomy, supports adaptive styles of coping and emotional regulation (Carlson & Sroufe, 1995). Therefore, support for autonomy from a caregiver can strengthen a child's sense of self and abilities for self-regulation.

Several studies also highlighted the importance of social connection and the role of autonomy in this. Studies suggest that individuals with BPD desire social connection but do not feel able to achieve this (Adler et al., 2012; Lind, Jørgensen, et al., 2019; Lind, Thomsen, et al., 2019). Autonomy was identified as a vehicle to social connection vital to recovery for BPD individuals (Kverme et al., 2019). These findings are not only relevant when considering high prevalence of social isolation in those with a mental health diagnosis (Wang et al., 2017), but also when considering the nature of BPD, in particular the experience of difficulties with interpersonal relationships (American Psychiatric Association, 2013). These findings highlight a perpetuating problem where those with a diagnosis of BPD seek social connection yet feel disempowered to achieve this, reporting and experiencing complex difficulties relating to others. Knowledge of the importance of social connection and difficulties achieving this in BPD are pertinent when considering the importance of the therapeutic relationship. A particular therapeutic alliance that (McMain et al., 2015), fosters client autonomy seems an important aspect of the therapeutic relationship in the context of BPD (Ryan et al., 2011).

Limitations

The included studies were considered to be of relatively high quality, as measured using the MMAT (Hong et al., 2019) with studies considered to be highly representative of the chosen population. However, this is likely a consequence of the inclusion criteria as it was a requirement for BPD samples to be identified using standardised diagnostic tools (such the Structured Clinical Interview for Axis II Disorders (SCID-II)). While this was aimed at establishing consistency and rigour in the study samples, such an approach excluded samples of people who were described as having BPD 'traits' or 'characteristics'. Grounds for screening out less standardised approaches may be unwarranted given there is a wealth of literature questioning the reliability and diversity of existing diagnostic categories and processes (Allsopp et al., 2019; Carcone et al., 2015). Screening out studies that did not use standardised measures may have precluded the incorporation of further information applicable to understanding autonomy in broader understandings of BPD traits. However, this would likely be at the risk of lower quality studies and greater heterogeneity of studies making comparisons between studies more difficult and less robust.

Cultural sensitivity is vital when working therapeutically with any clinical population, and BPD specifically (Neacsiu et al., 2017). It is noted that the included studies were conducted in the United States, Canada and other European countries. None of the included studies were carried out in the United Kingdom and this may have implications for the nuanced nature of studies and specific generalisation of findings between cultures. Furthermore, ideas related to individual autonomy may be a specific Western idea (Dove et al., 2017) and further exploration of autonomy in non-western cultures may be warranted.

The MMAT (Hong et al., 2019) was utilised for its ability and efficiency to critically appraise studies which have a range of methodological designs. However, there are reported to be issues in relation to its interrater reliability. While this limitation is acknowledged, there have been limited quality assessments available historically that enable broad coverage of studies (Pluye et al., 2009), suggesting such quality appraisals systems are in their infancy. Issues of reliability appear to be common to other similar quality assessment tools (Fenton et al., 2015).

Clinical implications

The current systematic review offers insights into autonomy in the development and clinical presentation in the context of BPD. By understanding factors that underpin autonomy and the importance autonomy plays in the clinical presentation of the clinical population, services will be more equipped to support individuals with a diagnosis of BPD. For example, understanding difficulties individuals with BPD may have had in early relationships with caregivers and ongoing interpersonal relationships, as identified in this review, may inform assessment procedures. Assessments should specifically aim to identify developmental difficulties with autonomy and how such difficulties continue to impact across the life span.

Based on specific findings within the review, it would be beneficial for assessments to focus on specific experiences of parenting styles and how individuals experienced parenting at a young age; this may provide information in relation to developmental failures of autonomy. When assessing current difficulties in relationships it will be important to establish aspirations for future relationships, alongside a sense of empowerment to change interpersonal relationships. A high desire to connect with others may be paired with a reduced sense of empowerment (autonomy) to achieve their relational goal. Information gathered based on the assessment protocol will directly inform intervention to focus on empowerment in relationships and barriers in forming connections with others. While psychiatrists may be more focused on diagnostic criteria in identifying symptomology to inform pharmacological intervention, clinical psychologists would be well positioned to implement specific assessment protocols given practitioner competency in a range of interventions.

Exploring patterns in productive and unproductive coping styles under-pinned by sense of autonomy may be helpful for clinicians working with individuals with symptoms of BPD as they identify the most promising routes to self-managed change (Kramer, 2014). In relation to specific therapeutic modalities DBT, MBT and psychoanalysis were identified within the current review. DBT was found to increase adaptive styles of autonomous coping (Kramer, 2017) while MBT and psychoanalysis were found to increase agency as identified through personal life story work by Lind & Jørgensen, et al. (2019).

National guidance stipulates mental health services should uphold autonomy when working with individuals with a diagnosis of BPD (NICE, 2009). The current systematic review may offer insights into the factors underpinning diminished autonomy and the problems BPD populations may encounter when accessing the care and treatment they require. For example, if individuals have experiences of attachment that has resulted in disempowerment, this may have implications for how they access services and how they form a therapeutic alliance. This is further highlighted in the literature in previous systematic reviews where attachment styles impact on the utilisation of mental healthcare services (Adams et al., 2018) and the therapeutic alliance (Diener & Monroe, 2011).

Human rights-based approaches to treatment will be useful for working with complex clinical populations as they are founded on facilitating meaningful, autonomous change (Donald, 2012). Clinical psychology has a key role in ensuring the implementation of rights-base approaches in the treatment of mental distress and in ensuring that rights of the individual are upheld during treatment (Butchard & Greenhill, 2015; Patel, 2019). Knowing that BPD populations are likely to have impacted autonomy related to parenting and attachment-styles, is pertinent to formulating an understanding of how an immature sense of autonomy may be a barrier to a therapeutic relationship and how they utilise services. The review indicates the importance of a therapeutic alliance that fosters autonomy. Attachment style and coping responses may be important factors; however, further exploration would be required to know specifically how autonomy could be a barrier to utilisation of services and in forming a therapeutic alliance.

Conclusions

Autonomy is complex and varied in individuals with a diagnosis of BPD. Not only are its features and its development highly diverse, methodological investigation of the construct is also varied. Parenting styles and attachment are pertinent to developmental impediments to autonomy in BPD. Shared concepts in the symptomology of BPD and autonomy include similarities in coping styles and difficulties with relatedness and helpful interventions to improve or address autonomy. The review findings highlight that autonomy plays a role in both the development of BPD and what helps to effectively support people with the diagnosis. Further psychological research will be vital in further exploring the phenomenon of autonomy in BPD particularly. Clinical psychologists have an important role in implementing knowledge gained from this research into how difficulties with autonomy in those with a diagnosis of BPD might develop, perpetuate difficulties in relationships and coping. In practice, it will be important to understand how difficulties with autonomy translate in therapeutic relationships and what interventions may be helpful to overcome problems related to autonomy.

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Chapter 2: Empirical Paper

Understanding Autonomy in a Specialist Community-Based Service for Borderline Personality Disorder: A Grounded Theory Study.

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Prepared in accordance with guidelines for submission to The Journal of Mental Health.

Abstract

Background: Autonomy is a key feature of a Human Rights-Based Approach (HRBA) and relates to an individual's self-determination and choice about what happens to them. Borderline personality disorder (BPD) is understood to result from invalidating environments and adverse early life experiences. Autonomy is considered to be a fundamental psychological need, one that is disrupted in those with display symptomology consistent with BPD.

Methodology: Grounded theory methodology was used to create a theoretical framework based on semi-structured interviews about experiences of autonomy for those with a diagnosis of BPD. Twelve interviews were conducted overall: five service users receiving treatment from a specialist community-based service and seven mental health professionals providing services.

Findings: The theoretical model conceptualises participant accounts as 'relational autonomy'. Autonomy is understood as dynamic and dependent on relationships and alliances with wider support systems. Important factors upholding an ideal sense of autonomy include: relational skill building, choice and involvement in care, empathic staff and services, flexible and responsive services and human rights and policy. Factors that challenge relational autonomy include: understanding and implementing rights; beliefs, attitudes and labelling; decision-making; the nature of BPD; risk; relationships with professionals and services; resources and service performance. These complex barriers are considered to have a significant impact on service users experience of accessing services and their sense of autonomy. As a result, service users may experience 'forced' or 'diminished' autonomy.

Discussion/implications: It is important for clinicians and services to recognise the importance of a structured and robust service model. One that fosters supportive therapeutic relationships where services work alongside service users to support decision-making and their recovery journey. Both service users and staff will benefit from improving their knowledge of Human Rights and how these inform mental health services. Human Rights-Based Approaches can inform decision-making and evidence-based interventions that are based on national guidance.

Key words: Borderline personality disorder, Autonomy, Human Rights, decision-making, therapeutic relationships.

Introduction

Borderline personality disorder (BPD) is characterised by emotional instability, identity disturbance, interpersonal difficulties and harmful behaviours that impact on daily functioning (American Psychiatric Association, 2013). BPD is thought to be the most prevalent subtype of personality disorder in mental health services, placing significant demand on resources due to the high cost associated with treatment (Dolan et al., 1996; McCrone et al., 2008; National Collaborating Centre for Mental Health, 2009; Rendu et al., 2002). However, the BPD label and its diagnostic process are highly contestable (Carcone et al., 2015; Reich, 1989; Zimmerman, 1994). Problems labelled as BPD are thought by many to be the understandable reactions to trauma, invalidating environments, emotional dysregulation and ongoing environmental stressors (L Johnstone & Boyle, 2018; Linehan, 1993).

Research has found that mental health professionals can express negative attitudes when working with people with a BPD diagnosis and simply having the diagnosis can alter mental health professionals' views (Rogers & Dunne, 2011). Psychiatric nurses consider those with a BPD diagnosis to be manipulative, powerful and dangerous (Deans & Meocevic, 2006; Woollaston & Hixenbaugh, 2008), psychiatrists have described the client group as difficult and undeserving of NHS resources (Chartonas et al., 2017; Lewis & Appleby, 1988) and some clinical psychologists have been found to distance themselves from BPD service users (Servais & Saunders, 2007). Negative attitudes have been found to impact care. For example, service users have reported discriminatory behaviour from health care services (Horn et al., 2007; Veysey, 2014) and psychiatric nurses can be less helpful to those with a diagnosis of BPD (Aviram et al., 2006; Forsyth, 2007).

Human Rights-based approaches

Human Rights Based Approaches (HRBAs) are drawn from the Human Rights Act (HRA) (1998) and provide a framework for translating the articles of the Act into good practice in mental health care (Curtice & Exworthy, 2010). Those with mental health difficulties are sometimes considered to have diminished autonomy in the context of temporary or partial impairments. This might be related to their judgement, reasoning, self-control and capacity to communicate their concerns (Radden, 2002). The Mental Capacity Act (MCA; 2005) states that a person lacking capacity is encouraged to participate in any decision affecting them and their care (Department of Health, 2005).

According to the HRA, not all rights are absolute, and some rights can be limited. It is important to understand when and why rights are limited and how these decisions are made, as HRBAs and respecting rights can positively impact care (Mansell & Beadle-Brown, 2004) and mental health. Conversely, violations of human rights can negatively impact mental health (Mann et al., 2016). Therefore, public authorities, such as the NHS, are legally bound to ensure rights are not violated and have a positive obligation to promote rights (Department of Health and Social Care, 2021). The FREDA principles, Fairness, Respect, Equality, Dignity and Autonomy, offer a structure for a HRBA (Curtice & Exworthy, 2010; DoH & BIHR, 2008).

Autonomy

Autonomy is a key feature of a HBRA and relates to an individual's self-determination and choice about what happens to them (Curtice & Exworthy, 2010). Autonomous actions are those initiated and regulated by the self, that a person willingly endorses (Ryan, 2005). Autonomy and self-regulation are considered to be the foundations for healthy development (Hartmann, 1958; Piaget, 1981; Werner, 1948). According to self-determination theory, autonomy, competence and relatedness are basic psychological needs required for personal fulfilment and self-organisation (Ryan et al., 1995). BPD is thought to be the result of a disruption to these basic needs in the context of unresponsiveness, invalidation and abuse by caregivers that thwart an individual's capacity for autonomy and relatedness to others (Ryan, 2005).

Whilst self-determination theory focuses on the individual, autonomy may be considered as created by, dependent upon, and exercised through relationships with other people. Such human interaction support autonomy to develop and flourish (Nedelsky, 1989). The critical nature of relationships in the experience of autonomy has led to the development of the concept of relational autonomy which emphasises the importance of social context and recognises individuals as inherently social (Christman, 2004; Nedelsky, 1989).

Autonomy is also highlighted in models of decision-making in healthcare, having moved away from ideas of paternalism towards autonomy and reciprocity (Pelto-Piri et al., 2013). A paternalistic approach assumes a clinician makes decisions about care and treatment, whereas approaches focused on autonomy assume decisions are made by the informed client. Reciprocity goes one step further and is considered necessary to support meaningful shared decision-making; it assumes there is mutual respect and collaboration between professionals and service users to provide opportunity for active participation in mental health care and planning (Charles et al., 1999).

Utilisation of Mental Health Services and Autonomy

Historically, mental health services excluded those diagnosed with personality disorder as the diagnosis was considered to be outside service remit. Services are now obliged to provide treatment to those with the diagnosis (National Institute for Mental Health in England, 2003). Following changes to legislation, and clinicians began to actively focus on inclusion in order to develop the most effective service designs (Bateman & Tyrer, 2004). The NHS and private sector have developed specialist personality disorder services where promotion of autonomy is a key recommendation (NICE, 2009).

The development of personal autonomy has been found to be important in the recovery process for individuals with BPD (Kverme et al., 2019; Shepherd et al., 2016). A therapeutic relationship that fosters client autonomy and collaborative engagement is fundamental in clinical practice (Ryan et al., 2011). In DBT, positive therapeutic outcomes, such as reductions in self-injury and suicidal behaviour have been found where therapists of BPD clients have exhibited warmth and were granting and nurturing of autonomy (Bedics et al., 2012a, 2012b; Shearin & Linehan, 1992).

The value of inpatient treatment for individuals with a diagnosis of BPD is a contentious issue and has yielded mixed results. Hospitalisation and repeated admissions have been shown to have a negative impact on BPD-related symptoms (Paris, 2004). New, innovative approaches to 'brief admission' aim to increase service user autonomy, self-reflection and self-care. This is achieved through the promotion of coping skills, early help-seeking, reduced time spent in hospital and avoidance of potential coercive measures and power imbalances between professionals and service users (Helleman et al., 2014; Strand & von Hausswolff-Juhlin, 2015). A 'brief admissions' approach has been found to have positive benefits for autonomy and self-efficacy, self-harm reduction, and equitable relationships with professionals (Helleman et al., 2018; Mortimer-Jones et al., 2019).

Current study

There is a gap in in knowledge as to how personality disorder services actively promote autonomy and fulfil their public service obligation to uphold human rights. The literature indicates that those with a BPD diagnosis are predisposed to diminished autonomy through exposure to invalidating environments and experiences of care (Linehan, 1993; Ryan, 2005). Despite national recommendations to promote autonomy, service users report feeling dependent on psychiatric services (Shepherd et al., 2016; Stapleton & Wright, 2017) and tensions in balancing personal goals for recovery with service targets (Katsakou et al., 2012).

There is evidence that promoting autonomy in service users with a diagnosis of BPD leads to better outcomes (Bedics et al., 2012a, 2012b; Kverme et al., 2019; Shearin & Linehan, 1992; Shepherd et al., 2016). As not all human rights are absolute, and there may be a tendency for services to restrict personal autonomy when problematic behaviours are seen. Little is understood about the nature of autonomy in this client group, and it is important to know how services respond to dynamic factors where autonomy is simultaneously problematic and the ultimate goal. Therefore, the current research aims to explore this dilemma and develop a model to understand service user autonomy in specialist personality disorder services. This will be informed by a HRBA to understand how individual autonomy can be upheld and how services respond and actively promote it.

Method

Design and Qualitative Methodology

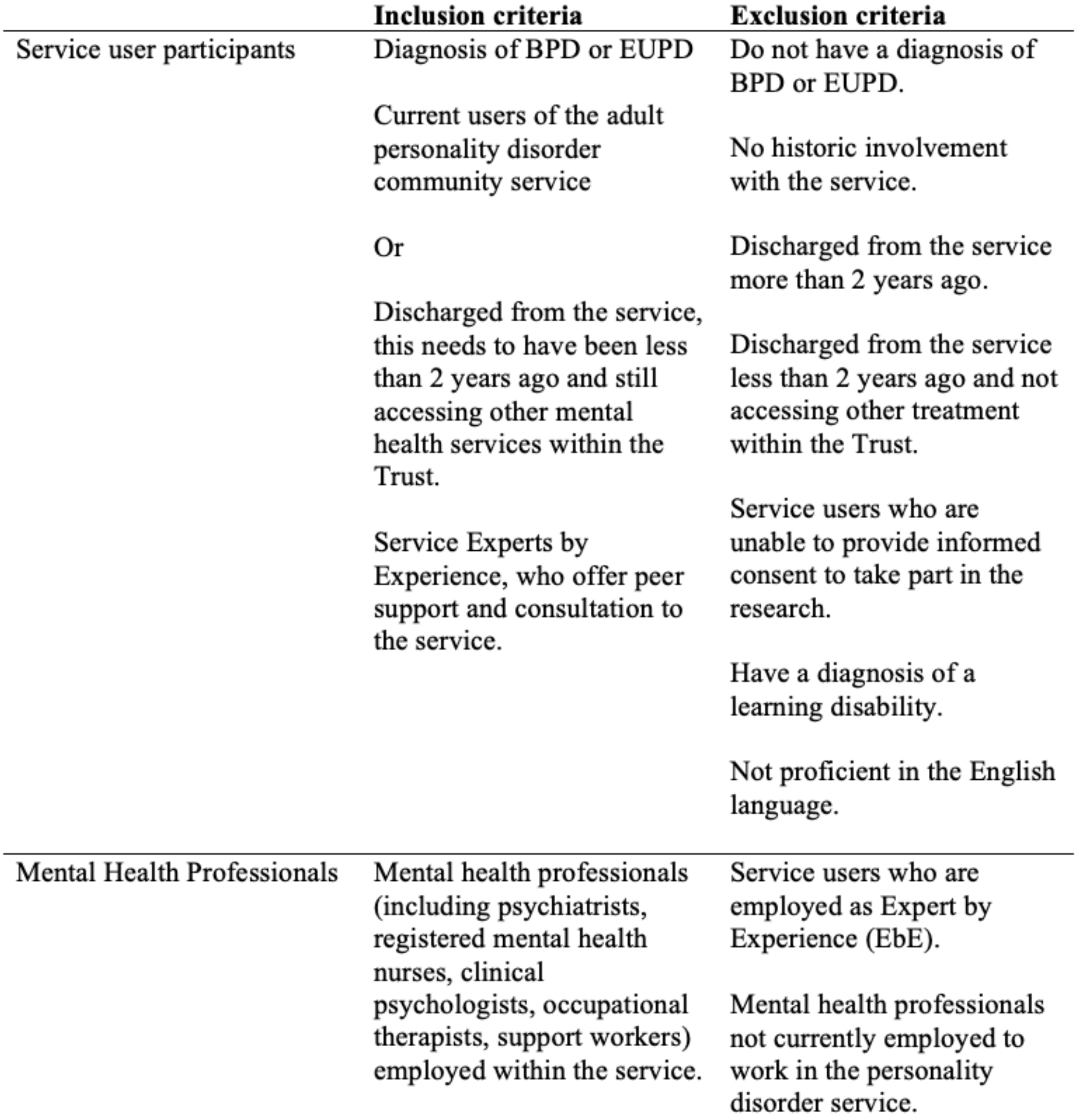
A qualitative approach was used to explore the experiences of autonomy in service users with a diagnosis of BPD and how staff, working in these services, promote autonomy. Given there is little known research in the field, qualitative research allows for the exploration of experiences and ideas for which there has been little prior research in order to provide rich data from which meaningful conclusions can be drawn (Braun & Clarke, 2013; Willig, 2013).

This research utilises constructivist grounded theory methodology (Charmaz, 2014) as there is little research on the field of BPD and experiences of autonomy. Grounded theory was used as it is structured, yet flexible and is useful when little is known about a phenomenon as it facilitates development of explanatory theory that uncovers processes present in the area of enquiry (Birks & Mills, 2015; Glaser & Strauss, 1967). Constructivist grounded theory focuses on how participants co-construct experience and meaning in relation to the area of inquiry (Charmaz, 2014; Charmaz & Bryant, 2011).

Recruitment

All participants were recruited from one NHS specialist community-based personality disorder service located in North England. Advertisements (see Appendix 5) containing relevant study and contact information were released through social media and distributed to service leads throughout the community service. Service leads were asked to distribute participant information sheets (see Appendix 6 and Appendix 7) to service users and mental health professionals who met the inclusion criteria (see Table 4).

Table 4. Participant inclusion and exclusion criteria.



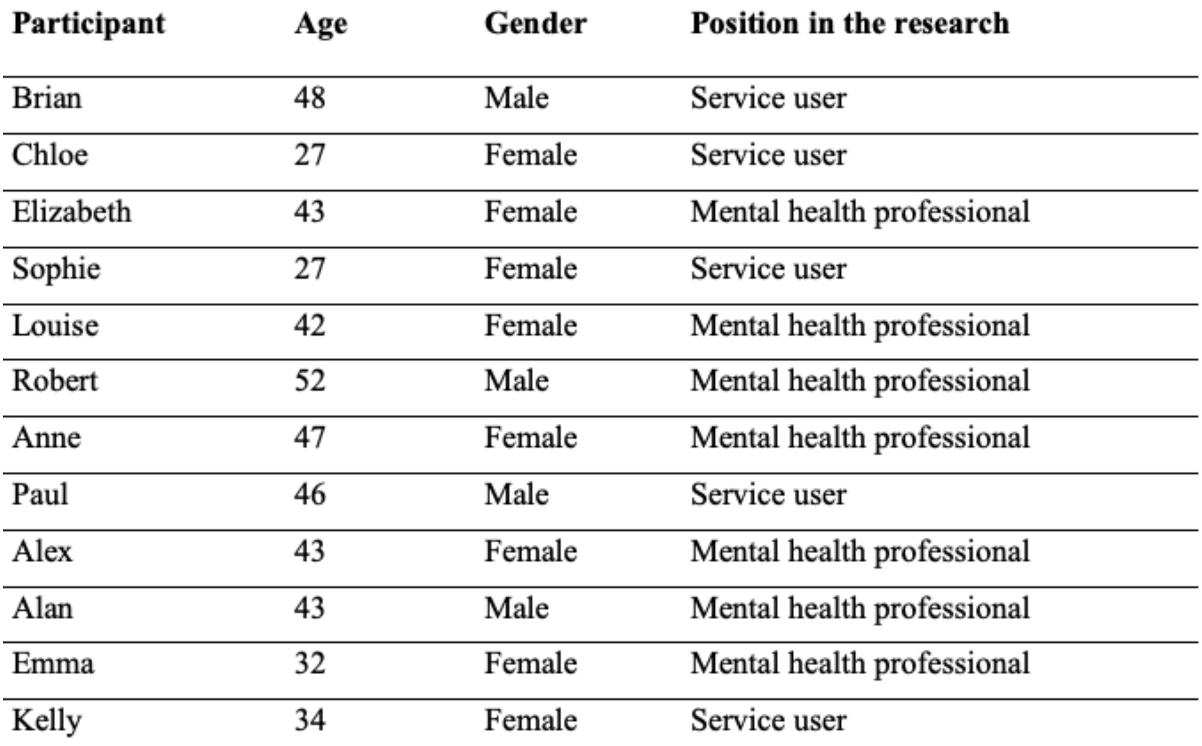
	Inclusion criteria	**Exclusion criteria**
Service user participants	Diagnosis of BPD or EUPD Current users of the adult personality disorder community service Or Discharged from the service, this needs to have been less than 2 years ago and still accessing other mental health services within the Trust. Service Experts by Experience, who offer peer support and consultation to the service.	Do not have a diagnosis of BPD or EUPD. No historic involvement with the service. Discharged from the service more than 2 years ago. Discharged from the service less than 2 years ago and not accessing other treatment within the Trust. Service users who are unable to provide informed consent to take part in the research. Have a diagnosis of a learning disability. Not proficient in the English language.
Mental Health Professionals	Mental health professionals (including psychiatrists, registered mental health nurses, clinical psychologists, occupational therapists, support workers) employed within the service.	Service users who are employed as Expert by Experience (EbE). Mental health professionals not currently employed to work in the personality disorder service.

When participants made contact to express interest in taking part in the study, they were offered an informal conversation (by telephone) with the primary researcher to discuss any questions relating to the research and their participation. Following these conversations, participants who wished to take part were sent consent forms by email or by post with pre-paid envelopes to return signed copies of consent forms.

Participants and Sampling

One service user and two mental health professionals were excluded from the study as they did not meet the inclusion criteria. Five service users and seven mental health professionals were recruited from and NHS community-based specialist personality disorder service. Staff member participants included clinical psychologists, psychotherapists and personality disorder link workers (see Table 5). All participants names are pseudonyms.

Table 5. Demographic information of participants.



Participant	Age	Gender	Position in the research
Brian	48	Male	Service user
Chloe	27	Female	Service user
Elizabeth	43	Female	Mental health professional
Sophie	27	Female	Service user
Louise	42	Female	Mental health professional
Robert	52	Male	Mental health professional
Anne	47	Female	Mental health professional
Paul	46	Male	Service user
Alex	43	Female	Mental health professional
Alan	43	Male	Mental health professional
Emma	32	Female	Mental health professional
Kelly	34	Female	Service user

Interviews and data collection

Qualitative data was generated through semi-structured interviews (Charmaz, 2014) which took place between October 2020 and March 2021 in the order outlined in Table 5. Interviews lasted between 40 to 90 minutes. Due to Covid-19 restrictions and social distancing measures, participants were invited to engage in interviews that took place using remote audio and video calling platforms. Participants were encouraged to use platforms where screen sharing was available to share information relevant to the interview process. No participants were excluded based on their access to technology. Two interviews took place over the telephone with written information emailed to them during the interview. Interviews were recorded using an electronic audio recorder.

The interview schedule (see Appendix 8) was co-developed with research supervisors and an expert by experience advisor in light of the research literature on HRBAs and legislative focus on autonomy. Questions at the beginning of the interviews explored participants understanding of human rights-based approaches and how this might be relevant to mental health care. It was anticipated that participant knowledge of human rights-based approaches would be variable. Following initial questions about their understanding of HRBA, participants were provided with information on HRBA to ensure they all began with the same knowledge of the subject. The short information pack outlined the Human Rights Act and its relevance to mental health care, FREDA principles, a definition of autonomy, a list of the Human Rights Articles, articles relevant to healthcare and absolute articles (see Appendix 9). Subsequent interview questions focused on how service user autonomy is upheld within specialist services and service user experience and insight into their own autonomy. Questions for mental health professionals focused on how they, and services, strive to uphold and promote autonomy. Participants were interviewed in the order shown in table 2.

The interview schedule was updated after the first five interviews were conducted (see Appendix 10) to increase theoretical sensitivity and enable greater data saturation and richness within emerging categories. Questions were adapted to allow greater focus on understanding broader insights into participants' understanding of autonomy, autonomy development, participant opinion on why they think autonomy might be a key issue in BPD specifically and opinions on why the client group might struggle with autonomy.

Both the initial interview schedule (Appendix 8) and the updated schedule (Appendix 10) appear structured in nature to fulfil the requirements of NHS ethical committees to have a clear topic guide with example questions. However, the interview was conducted in semi-structured style and was conversationally based to allow flexibility and an iterative approach to data collection.

Data analysis

All twelve interviews were audio recorded and transcribed verbatim. Identifiable information removed and participants were assigned pseudonyms to maintain confidentiality. Transcript data were read closely and examined for potential meaning. Short narrative summaries were produced for each interview to support the reflective process and development of the final model (see Appendix 11 and Appendix 12).

Analysis followed the procedure for constructivist grounded theory outlined in Charmaz (2014) and followed three stages of coding: initial coding, focused coding and theoretical coding. Initial coding requires that data are coded line-by-line to generate as many codes as possible. Initial codes integrated actions and social and psychological processes and were kept as similar to the data as possible. Focused coding built upon the initial codes to allow integration and synthesis of larger amounts of data. Focused codes were synthesised further to create theoretical categories to inform an emerging theoretical model. The process of constant comparison was followed and early initial codes were compared with other codes and emergent theoretical categories were continually compared with earlier emergent codes (Birks & Mills, 2015; Charmaz, 2014; Glaser & Strauss, 1967). Appropriate adjustments were made where required. Memos illustrating the process of theme development are available in Appendix 13.

Data gathering is continued until data sufficiency is reached and when no new categories are constructed in light of new data (Dey, 1999). This was difficult given the time constraints of the DClin and ongoing barriers associated with the COVID-19 pandemic and a total of 12 participants were recruited. However, based on the data analysis of 12 interviews, the data and associated categories were considered robust to account for patterns in the data.

Memos were written to help document and formulate ideas related to the coding and theory development process, while interacting with the data (Glaser & Strauss, 1967). In the current study, memos were utilised similarly to a research diary and enabled to the keeping of an audit trail of ideas and how this related to their own position in the research (see Appendix 14).

Quality assurance

The credibility criteria outlined in Charmaz (2014) and Elliott et al. (1999) were used to guide the research design and data analysis process. The guidelines emphasise the importance of transparency in relation to the researchers personal, theoretical and methodological orientations to the research (see Appendix 14 for reflexive statement).

To further ensure credibility, the primary researcher received regular supervision and consultation from supervisors and engaged in consultation with an expert by experience. Research supervisors received transcripts and coding frameworks for each level of analysis and reviewed the final theoretical model. The primary researcher engaged in memo writing and kept a reflective journal throughout the research process.

Reflexivity

Finlay & Gough (2003) highlight the importance of reflexivity in qualitative research. This is particularly important for a constructivist approach to grounded theory, where the researcher is actively engaged when interpreting the data during the analysis process (Charmaz, 2014). The reflexive statement offers insight into the primary researcher's background, clinical experience and specialist interests of working with individuals with a diagnosis of BPD, potential theoretical influences including interest in HRBAs relevant to the current study.

Expert by Experience Consultation and Participant Feedback

The Liverpool Expert by Experience group were consulted in the planning stages of the research. The expert by experience consultant supported the research team and this was someone who was also a highly specialist peer support worker within the Trust and service in which participants were recruited. The expert consultant was directly involved in the design of the research design and development of topic guide.

Following completion of interviews and data analysis, all participants and the expert consultant were invited to feedback session. This process supported the development, validation and conceptualisation of the research process and theoretical model. A narrative summary was provided to all participants (see Appendix 15).

Ethical approval

Ethical approval for this study was granted by Research Ethics Committee Wales REC-7 and Health Research Authority on 9th June 2020 (REC reference 20/WA/0151) (see Appendix 16).

Participants expressed their interest via email or telephone. Information packs were sent in the post that included participant information sheets and consent forms (see Appendix 17 and Appendix 18). All participants were offered individual time with the principal researcher (RG) to discuss any questions or concerns related to the research. Participants were asked to return sign copies of consent forms in the post.

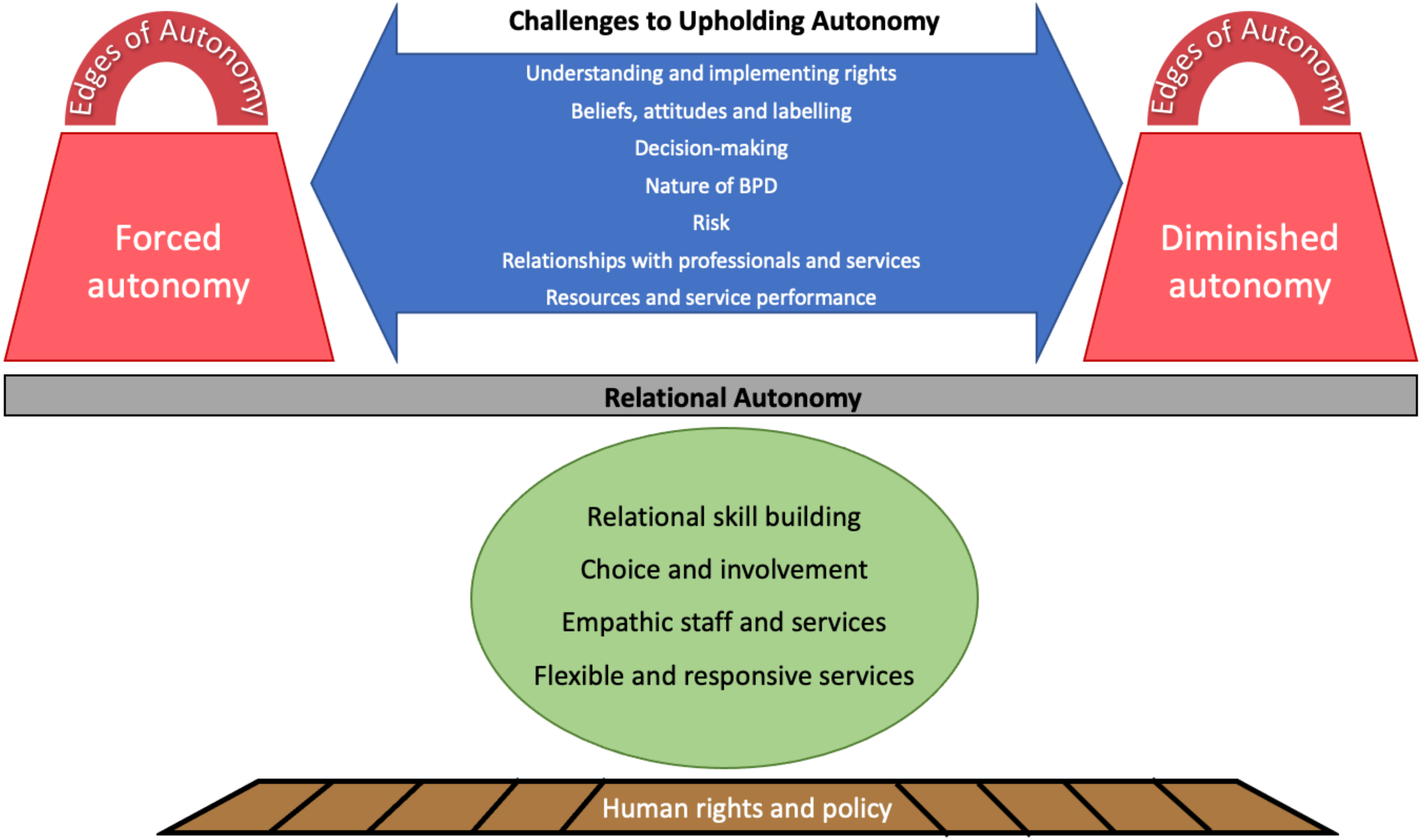
Service users were informed that their care team would be told of their interest to take part; this was contained within the consent form. Care teams were contacted to establish whether the service user was currently accessing the service or had previously done so (a key inclusion criterion).

Results

Figure 2 portrays an explanatory model of the research findings. There are three theoretical categories: relational autonomy, edges of autonomy and challenges to upholding autonomy (Appendix 19 outlines the coding structure). Relational autonomy is depicted as a plinth carefully balanced on a sphere, rolling on a track. The precarious balance of the plinth reflects the dynamic nature of factors contributing to the sustainment of relational autonomy. Factors maintaining relational autonomy are: relational skill building, choice and involvement in care, empathic staff and services, flexible and responsive services and human rights and policy.

The plinth can become off balance, each end made heavier by opposing 'edges of autonomy'. As a result of 'challenges to upholding autonomy', an individual with a diagnosis of BPD may experience elements of 'forced autonomy' or 'diminished autonomy'. Challenges to upholding autonomy include: understanding and implementing rights; beliefs and attitudes; decision-making; the nature of BPD; risk; relationships with professionals and services; resources and service performance. The following sections outline individual aspects of the theoretical model. Additional quotes can be found in Appendix 20.

Figure 2. Model of ‘Relational Autonomy’.



Relational autonomy

All participants described aspects of services and treatment that contributed to relational autonomy. Autonomy was described as relational as it was not considered to be purely dependent on one individual. Instead, autonomy was dependent on dynamic factors involving supportive relationships and networks. Five focused codes are elaborated below that outline participants' descriptions about their experience of what factors contributes to relational autonomy.

Relational skill building

All participants spoke about the development of vital coping skills and the importance of having a variety of evidence-based interventions suited to the needs of service users. Mental health practitioners described how national guidance translates into psychological intervention for BPD that encompass three therapeutic modalities: Mentalization-based therapy (MBT); dialectical-behaviour therapy (DBT); structured clinical management (SCM). Interventions were designs to support the development of autonomy and necessary skills to the client group to be able to learn to cope independently and live autonomously. Professionals were mindful that they did not want service users to be reliant on them, and services. Support for skill building was described as a lifeguard metaphor where mental health professionals worked alongside service users, being careful not to take on a 'rescuer role'.

"If you teach somebody to swim, every time you teach someone you're in the pool with them, you're just holding them up out of the water, but if you can be on the side of them, talking them through to swim they're going to learn to swim, rather than you be in the pool with them and showing them what to do" (Alan, mental health professional).

This was felt to be important because:

"They'll learn how to deal with it rather than somebody telling them what the right way and the wrong way is to do, so you're more likely to get, a more autonomous person rather than somebody maybe more reliant on services…" (Alan, mental health professional).

In response to the availability of a variety of therapies, service users found it helpful that there was a range of interventions to suit their needs, and they had the option to change therapies if they wished.

"I tried structured clinical management and the time wasn't the right time, the intervention was disrupted…and at that time I needed structure. So, I said, this isn't right for me and they changed my therapy. I found that one wasn't right for me, so they've changed my therapy again, and the one that I'm finding now, erm, I'm currently doing MBT, and I find that, that's not right for me because I want one that, is sort of skills based, erm, and I've asked to, change therapy" (Chloe, service user).

Choice and involvement

All participants spoke about the importance of service users being able to have choice in their care and decision-making across different aspects of their lives. Professionals spoke with passion about the right of service users to make their own decisions, irrespective of whether others agreed with their choices. There was acknowledgement that it can be challenging for service users to take ownership of their care and treatment and more general decision-making.

Where service users needed support in their general decision-making and about their treatment, professionals tried to ensure this was a guided, collaborative approach. It was important to provide service users with sufficient information to make informed choices. Professionals spoke about providing leaflets to participants that described the service and treatments available. However, collaborative decision-making was more than providing information and professionals described working alongside service users to actively support and guide them in their decision-making.

"So that they can make a decision, and getting alongside of people to, weigh up, the pros and cons. I do think that's part of our responsibility as health care professionals, rather than, particularly when people might struggle with problem solving, rather than, just giving the information sheet for people to go and read, in their own time, when it might be difficult for them to prioritise time to do that. I think we've got a responsibility to support that decision making process" (Emma, staff member).

Similarly, service users felt it was important to have support in making decisions about their care and appreciated being able to have ultimate choice.

"Left the last word with me really which one did, they give me the sort of benefits and, erm, potential risks with them and, and really let me make the final decision really on which, one I wanted to go for" (Kelly, service user).

Although treatment choices and relational skill building were key aspects to building autonomy, it was also important for service users to be able to express when they needed more intensive support. Service users spoke about wanting to avoid hospital admissions, and mental health services being in agreement with this. However, there were times where hospital was an active choice, but service users still required support with this process. Although, this may be considered as having their autonomy taken away however, service users experienced greater autonomy in being able to make this decision alongside professional support networks.

"*That was my, that was my choices, to be kept out of hospital as long as I can, but I got to a point where, I turned round and said to them, I said, ' I can't do this anymore, like I need, I need to go into hospital', and they did, they facilitated that"* (Chloe, service user).

Empathic staff and services

All participants contributed to the theme of empathic staff and services. Mental health professionals were aware of the need to create an empathic and validating therapeutic environment.

"I think that's the, that's the first point, so you'd, when we talk about creating, listening, stop and listen, I just like sometimes from my perspective, I listen, listen and, validate their distress so you 're just trying to understand, so listening and then validating so just, you know, if depending on, based on that situation you, you'd validate the person, you'd listen…" (Alan, staff member).

In response to this, service users spoke of their positive experiences, when they felt heard and supported*, "It just makes me feel, valued really, and like there's someone there that understands and generally wants to help me… I just feel, you just feel like you can really open up without being judged"* (Kelly, service user).

Service users reflected that being listened to this had a positive impact on their wellbeing and self-worth, *"Makes me actually think well I might be worth something here, you* *know, someone's spending the time to actually look what's going on with me. Erm, maybe I can like, join in with that"* (Paul, service user).

Flexible and responsive services

A clear, consistent, and responsive service model was considered to provide containment to both service users and mental health professionals. A containing systemic approach supported service users, who may otherwise feel overwhelmed, due to the nature of their difficulties in managing their emotions.

"They have so much going in their mind, that they're in this sort of sense of overwhelmed-ness and they're not sure what's best for them, and they're making decisions based on threat mode. The best thing we should be able to do is offer them a consistent, coherent, continuity focus care pathway, that is collaborative in communication. And that's how the service works…you give people this organised olive branch" (Robert, staff member).

Having a clear and consistent service structure also helped mental health professionals to feel contained and supported in their clinical practice and decision-making, *"…feeling like you've, really been supported to consider a decision thoroughly and that you've got a clear rationale for why you're making the decisions you are, helps decision making to feel, safer, and a bit more, supported and contained"* (Emma, staff member).

A parallel process was identified where the support available to professionals was also what they were trying to instil in service users, in order for them to develop their own autonomy.

"The fact that that's what helps me to feel more comfortable being autonomous in my role, is actually the fact that I've got that support. And that's exactly what, I would hope, we mirror, with service users. But I'd never thought of it in that way before, but I do think that's, that's what allows me to feel autonomous" (Emma, staff member).

Although participants described a clear service model as containing for both staff and service users, there was also some flexibility built into the service model. Professionals had to have a strong rationale for stepping outside of the agreed framework, but structures were available to allow them to do this in a safe and supportive way.

"You can go out of it, but you have to make a case to go outside of it… if I'm going outside it and I'm making a case that's already, there's already that clear rationale of why I'm doing it" Elizabeth, staff member).

Human rights and policy

During the interviews, all participants were provided with a standard summary of HRBAs and the FREDA principles. This enabled participants to reflect on their understandings in more detail and consider how rights fit within healthcare. In the current study, human rights and rights-based approaches were considered fundamental to healthcare and underpinned specific services offered to individuals with a diagnosis of BPD, *"The whole Pathway is about, empowerment, Autonomy and choice. Yeah, that's the fundamental philosophies underneath all our principles"* (Robert, mental health professional).

Service user participants also demonstrated their own awareness of human rights and there was an overall sense of equality being a fundamental principle, *"...from a personal human rights point of view, I think that we've all got a right and an equal right to be, you know, to be listened to and to be heard… Nobody has the right, for me, over any other man. Wealth or not, wealth or power or no power"* (Brian, service user).

Alignment of human rights within healthcare policies, standards and legislation was imperative to upholding relational autonomy. Participants made links between human rights principles and how this translated into concrete examples of rights-based practices in specialist personality disorder services.

"Human rights is people's freedom to, speak up, in terms of their needs, their wishes, whether that's a spiritual need, whether it's like a family member, some people's rights within, and I guess within, within where I work it's within that legal frameworks as well. Whether that's kind of accessing information or…wanting to see, kind of, what their, their care pathway looks like, their right to kind of, duty of candour, or to be honest and upfront, lots of, I guess there's lots of different forms" (Louise, mental health professional).

Although they made explicit links, human rights were also considered to be implicit and a concept that informs services and professional standards.

"Everyone's got Human Rights, haven't they? It's like an unwritten rule" (Sophie, service user)

"It's probably worded differently within healthcare, and they might not name it as Human Rights. They'll probably name it, in policies as something else, so we don't think about it as, someone's Human Rights, we probably think about it as a policy… something we have to do in terms of like, code of conduct for nursing or, you know your registration, erm, so I'm governed by that, in, in my health practice, which is people's Human Rights, but it's named differently isn't it?" (Louise, mental health professional).

Challenges to upholding autonomy

Relational autonomy is dynamic and precarious and several factors contributed to the prevention of 'ideal' relational autonomy being upheld. Where relational autonomy was tipped off balance, service users experienced the 'edges of autonomy'. This 'tipping over' was considered a result of overpowering factors including: upholding and implementing human rights, differences in attitudes and beliefs, poor relationships between service users and professionals, challenges in decision-making and managing risk, limited resources and problems related to the nature of BPD. A complex combination of these factors and types of challenges determined which pole service users might be more likely to find themselves in; either 'forced autonomy' or 'diminished autonomy'.

Understanding and implementing rights

Participants expressed how human rights where integral to relational autonomy and how it could be applied to healthcare, detailed within 'human rights and policy'. However, this awareness was prompted by the written information provided to participants. Without the written information and where participants were more reliant on their existing knowledge and lived experiences, both professional and service user participants expressed that, overall, they had limited knowledge of human rights and how these applied to healthcare.

"I will read up on this stuff but, I dunno why I've never like, even tried to understand any of this, it's weird, it's weird now, now that you're showing me it, it's like a little light going on

inside me head, I'm thinking, like, why, why haven't I, never even looked at this before? It's weird…" (Paul, service user).

Professionals acknowledged that human rights approaches can often be implicit and assumed. This was considered potentially risky, if rights were not always at the forefront of their mind. If there is limited understanding of rights, it may be challenging to implement and uphold rights. For service users, limited knowledge of rights was because it had not been explained to them.

There were specific grey areas for services offering support to client groups with a diagnosis of BPD. For example, upholding autonomy and rights often meant withholding care.

"You're into all sorts and grey areas, so that's really confusing. So, although our Pathway is about that, I think it can be misused as well in a sense. I think empowerment, choice and autonomy can be, often used to withhold care, ironically, rather than, offer" (Robert, mental health professional).

There was a common dilemma between liberty and autonomy and practices that demonstrated the dynamic nature of autonomy. Autonomy fluctuated and was not definitive. Service users may choose to have their liberty taken away and opt for a hospital admission. However, this conflicted with professionals' values as taking away liberty was synonymous with removal of autonomy. However, for a service user, choosing to have their liberty taken away was an autonomous choice.

"I think sometimes we get service users have right to lose their freedom, and we are actually trying to build autonomy, and actually, they say 'no, you've got to put me in hospital'...there's a conflict in some of these values actually. So, I'm trying to say, 'I wanna help you build autonomy' and they say, 'no actually I can't manage me, I need to be locked up, and have my liberty [taken away]'. So ironically although it can go one way, sometimes, it's, it's, their, you know, if you've got the choice, versus autonomy, versus freedom, and they aren't always, going together" (Robert, mental health professional).

Beliefs, attitudes and labelling

All participants acknowledged the impact of negative attitudes towards individuals with a diagnosis of BPD. While specialist services appeared to hold more positive attitudes and empathy towards the client group, service users experienced stigma and negativity from wider services. This impacted on their interactions with services, the care they received and ultimately on their ability to develop relational autonomy.

"*I've not long come out of being in-patient and I was in a private hospital, and I found that the consultant there was very, anti-personality disorder. I got called manipulative, another girl with personality disorder, she got called attention seeking and I think it has negative impact on the care that you will receive"* (Chloe, service user).

Service users spoke about being treated differently to those without the diagnosis of BPD, *"Yeah, and I have had massive issues with the whole treatment team, and the crisis team. So, I very often, like in the early days when I couldn't sit with the feelings and I was going straight to suicide or ligaturing most days, erm, I'd ring them up and just because of my diagnosis it's like, oh you're always suicidal. Do you know what I mean? Where, I don't feel like we're treated the same as other people without the diagnosis"* (Kelly, service user).

Service users also felt that the diagnosis was used against them, ***"****I feel like sometimes, I know that they're a mental health service and they're supposed to be helping people with mental health problems, or diagnoses or, whichever, erm, it just feels like sometimes they kinda use it against me"* (Sophie, service user).

Negative attitudes where thought to be due to a lack of understanding and knowledge about the client group**,** *"...My big thing at the minute is like education, and awareness of staff. Erm, I've been working on the PD Pathway for like 12 months, and I didn't have a clue what PD Pathway was before I came into this job, and I know that other practitioners, in, in many other teams, you know, it's not even just a particular part of the services, don't have a clue. They don't have a clue… for what the PD Pathway is"* (Alex, mental health professional).

Risk

Participants spoke about the difficulties of balancing risk. Risk of self-harm and suicidality was acknowledged as common aspect of symptomology of BPD and was a challenge to upholding relational autonomy. For example, mental health professionals spoke about fears associated with positive risk-taking and anxiety of someone coming to harm and being to blame.

"I guess from a mental health perspective I think, erm, people, lots of mental health practitioners struggle to, erm, take positive risks, because, of the, the fear that something might happen to somebody, and then they'll be liable for that" (Alex, mental health professional).

Anxieties from mental health professionals often led them to implement more restrictive care methods, such as hospital admission. Emotive reactions and reliance on restrictive care contributed to a sense of diminished autonomy.

"Some of their decisions, you, cause anxiety for us, and other people, then that can lead us to get into, restrictive care, that, sometimes, isn't also to be over maternal or paternalistic and then disempower the service user as well" (Robert, mental health professional).

Service user participants spoke about being on the receiving end of overly restrictive care and spoke about how staff responses to increased risk was difficult to understand. Service users spoke of their experience of living with experiences of suicidality and how restrictive care, such as hospital, was not always helpful and did not change their level of risk.

"I did sort of find it really hard to understand because it was like, no you can't leave, because you're suicidal, but I live outside, suicidal all the time" (Kelly, service user).

Decision-making

There were instances where decisions were taken away from service users and this process required careful navigation. Where inappropriate action was taken and decision-making was deemed insensitive and service users lacked involvement, this increased the likelihood of service users experiencing the 'edges of autonomy'. Maintaining the balance of relational autonomy was challenging when service users may be unable to make decisions. There were times when they required additional support and when services were required to step in and make a decision for them.

"There'll be sometimes when, people might, want the information and want to make a really clear, thought out decision, and there'll be other times when people just feel overwhelmed and, not able to make that decision and, just want to feel cared for, want somebody to take that pressure away from them, and make the right decision for them" (Emma, mental health practitioner).

The decision-making process appeared to be precarious. While mental health practitioners may carefully consider decision about treatment, services users may not feel involved and feel excluded from decision about their care.

"So there would be a lot of, so it's like there was, things happening and decisions that I wasn't, was totally not part of...I was on a voluntary, section and say I want to leave, and they was basically, threaten me with a section, and say well, if you do want to leave, we'll go and get the paperwork now and we'll have to section you" (Kelly, service user).

Nature of BPD

All participants had an understanding of how life experiences contributed to a diagnosis of BPD. Mental health professionals spoke about how trauma experiences contributed to the development of specific difficulties related to autonomy for those with a diagnosis of BPD.

"A lot of people with a diagnosis of BPD have a, have a trauma background, not all, but a lot of people have a trauma where that's been controlling and their autonomy's been took away" (Alan, staff member).

Mental health professionals had clear ideas about the purpose of continuing to promote autonomy as they believed it helped to reduce further re-traumatisation.

"So, if someone feels controlled, they lose autonomy, it reinforces trauma, so if you can, if you can, promote autonomy then you're less likely to re-traumatise somebody" (Alan, staff member).

Although mental health professionals had clear ideas about the development of difficulties and treatment approaches to uphold autonomy, service users presented with complex and unique difficulties that perpetuated challenges in upholding relational autonomy. Service users reflected on how their low self-worth impacted their ability to stand up for themselves which was related to their own personal experiences of autonomy.

"…If someone automatically takes a one up situation with me, I won't stick up for me self, and I can be railroaded, and I have been railroaded like loads of times and you're like because…Its, I think it's down to self-worth as well, cos I've got, I haven't got any. It's easier for me to just to, to, to say, 'yeah alright', even though it's not what I want or not what I think's best for me" (Paul, service user).

Participants conceptualised autonomy as fluctuating and this was an important aspect of their ongoing difficulties in developing and maintaining autonomy. Mental health professionals reflected on their own fluctuating autonomy as a way to understand how service user will undoubtedly have similar experiences.

"There'll be times in my life where, I'm very headstrong and I want to make, all decisions myself and, I, will be really passionate about that, and want to feel independent and in control and there'll be other times when, actually it feels overwhelming and, and I just want somebody to give me the answer and to resolve it and, I think, that's just being human" (Emma, staff member).

Relationships with professionals and services

All participants spoke of examples of poor relationships between service users, mental health professionals and mental health services. Examples of poor relationships were particularly evident from service users experience of inpatient wards and communicating with crisis teams. Service users often felt that some, less specialist, mental health professionals invalidated their experiences and did not know how to help. Unhelpful relationships and power imbalances with services could lead service users into the 'edges of autonomy'. For example, where service users felt unheard and misunderstood, led to 'forced autonomy'. Service users spoke about the negative impact of the power imbalance between mental health professionals and service users.

"They just kind of, think they think that they're more superior for me, like there's no sort of equal grounds really" (Sophie, service user).

Specialist mental health professionals were aware of the power imbalance and the potential negative impact this might have.

"*If you come with someone who has got a very dictatorial stance, if you're already thinking, I'm not worth of anything, and I'm not valued, where, where, how is that dynamic gonna play out"* (Anne, staff member).

Power imbalances may also re-enact trauma experiences, *"…We are still in that powerful position and they're still in the powerless position. Which is a problem when you're looking at people who had complex trauma whereby their carer, has been the abuser as well"* (Robert, staff member).

Mental health services aimed to avoid power imbalances, however, there was an acknowledgement that some power differences were unavoidable as professionals were required to draw on their expertise to support and guide service users.

"*I'm aware, there's a power dynamic, in, the interaction that we have with people accessing the service, and, it's a fine line because to some extent you're drawing on your professional knowledge, erm, and advising the best course of action"* (Emma, mental health professional).

Service performance and resource

Mental health professionals described how inconsistency in service performance impacted service ability to promote autonomy through appropriate interventions. Service users felt that poor and unreliable services impacted them negatively.

"It's like *a pick and mix, it just depends what ward you get. What the person's presentation is, what they, you know, what is best for that person. Whether they feel restricted or not restricted"* (Alex, staff member).

While participants had previously spoken about the importance of specialist services as being supportive and containing, and this was underpinned by policy and human rights approaches. However, participants also spoke of how services were limited by the guidance and policy as to what interventions they could offer.

"You've got guidance from NICE, National Institute Clinical Excellence, you've got what's recommended, so you've got three treatments, erm to offer, so you are limited in theory to what is recommended based on what we offer, so there is a limit" (Alan, staff member).

Within 'relational autonomy' mental health professionals had spoken of being able to offer bespoke services if the standard interventions were unsuitable. However, there were instances where if service users did not want one of the treatments offered, there might be no other treatments to choose from. Although this was considered to be a clinical decision made by mental health professionals, it may be experienced as dismissing to service users, potentially leading them to experience 'forced autonomy'. Service users could be added to extensive waitlists and mental health practitioners spoke of how lack of resource may impinge on the human rights of the service user, as they were limited in choice and not having access to treatments in a timely manner impacted on autonomy.

"Some people have been waiting a long time for the interventions. Just because there's nobody to do them, so, which that probably does infringe some of their rights to a degree" (Elizabeth, staff member).

Edges of autonomy

When faced with the complex, and aforementioned, challenges that impacted the sustainment of relational autonomy, service users were described as being likely to fall into two possible categories: 'forced autonomy' or 'diminished autonomy'. While there are two poles, the balance was fluid and not necessarily definitive. Service users may 'flip between' the two.

"…If you look at people with complex relational emotion, borderline in the guideline is, assumption capacity. Now the idea being is, if we treat people as adults, that's gonna build the adult mode in them, you know. So, let's not try and treat them as too fragile and assume their

decisions….But there's a counterbalance to that…one of the other things is about realistic expectations, and this is the, at times, the person may really struggle, to be able to manage that and we may need to be more proactive to helping them. You're trying to manage that balance, if there's an assumption of capacity, versus realistic expectations and there needs to be a subtle fluidity in that, and then you get back to the, you know, status quo as quickly as you can. But that's quite hard, for all of us, when you're in a crisis, to keep in mind. I think sometimes we flip between, assuming too much capacity for too long, or, treat the person as too fragile" (Robert, mental health professional).

Forced autonomy

Mental health practitioners spoke about how there was often an assumption of capacity and this was linked to service users sense of autonomy. While assumption of capacity was important and fundamental to mental healthcare, there was recognition that the assumption of capacity and autonomy being related may be misguided. Service user participants spoke about their experience of autonomy being 'forced' on them.

"They almost want me to have autonomy when you've not. When you're not capable of it. Do you know what I mean? They're like, well you know, it's your, you've, it's your decision, you know, you, you're responsible for your actions and stuff where, at them times I'm not. I'm actually not….when I really need them and I've not got autonomy, then they, they're not there for me, they're forcing it on me" (Kelly, service user).

Mental health professionals may aim to uphold autonomy through the assumption of capacity, but service users spoke of how this was experienced as being abandoning. Service users had previously commented on the unhelpfulness of the crisis service and how they were often unable to have contact with some mental health professionals in between sessions. As a result, service users felt they were not listened to, and their needs were not being met by mental health services.

"*I just felt like, I was very lonely at that time, like, with, the support and then, like I felt really let down by them. Cos like I needed them, most and they weren't there, they didn't support me*" (Sophie, service user).

Feeling unsupported, service users commonly responded in one of two ways; withdrawing and retreating from services or increasing risk as being an instrumental way to receive the care service users desperately needed. Sophie (service user) demonstrates these two responses:

"Like, sometimes I feel like a bit of a burden, so I just don't seem to ring them anymore, just, yeah, it does feel like I'm a bit unwelcome, like, of their support".

"I feel sometimes, like, if I, if they say to me, 'are you safe?', I feel like the only way of me getting that extra support is if for me to say, 'no I'm not'. And then they would step up, but it shouldn't get to that, and I don't lie, so, like it shouldn't get to that".

Diminished autonomy

Service users may be at risk of becoming disempowered through their over-reliance and dependence on mental health services. Mental health professionals spoke about how they may want to rescue a service user and make decisions for them but his was viewed as disempowering.

"I've seen, numerous examples of where, mental health services can fall into doing to, and almost disempowering people…" (Emma, mental health professional).

While being 'rescued' may be preferable for a service user, they may feel held in mind and well supported by their care team. However, this way of working was thought to deskill service users and negatively impact their mental health.

"When, when I'm feeling overwhelmed with emotion and feel like, you know, feel like harming myself, the only way I can cope is if I phone up, you know someone, and she tells me what to do, rather than…Yeah, yeah, over time it deskills and un-skills, and deskills you rather than…So, in some ways you could say it makes people worse" (Elizabeth, mental health professional).

Part of diminished autonomy was service users having decisions made for them, and professionals recognised this as being over-protective.

"Decisions are made on their behalf, but actually, people have got capacity erm, and they might be poorly or they might be self-harming, and they might be in hospital, but actually then they've got decisions that they, that they can make, erm, and actually sometimes their decision to self-harm you know is, is their decision to make as well and, it feels like we often, er, are very over protective in that respect" (Alex, mental health professional).

Although it might feel preferable for a service user to have strong therapeutic relationships with one professional, staff participants recognised the dangers of this.

"It tends to be that people can become reliant on that one person and if that one person goes off sick or leaves or has a baby or whatever then then that's when, anecdotally anyway, certainly…I don't know if there is, I'm sure there probably is evidence to support this as well…that's when people would have, would go into crisis" (Elizabeth, mental health professional).

Discussion

The current research aimed to explore service user experience of autonomy in mental health services and how these services promote autonomy. These perspectives were investigated in the context of fluctuating behavioural patterns and the complex clinical presentation of BPD and in the context of national guidance (NICE, 2009). The literature indicates that those with a BPD diagnosis may have difficulties in exercising their own autonomy due to exposure of invalidating environments and experiences of care that do not foster autonomy (Linehan, 1993; Ryan, 2005). Given that some rights can be limited and are not all absolute, the model was informed by a HRBA to understand the balance between individual autonomy and how services respond to actively promote it.

The study adopted a grounded theory approach to support the development of a theoretical model of relational autonomy. A theoretical model was developed to understand service user autonomy in such specialist personality disorder services. The final model incorporates three theoretical categories: relational autonomy, edges of autonomy and challenges to upholding autonomy.

The literature highlights autonomy as a core aspect of recovery for individuals with BPD (Johansen et al., 2017; Shepherd et al., 2016). The current findings emphasise the importance of autonomy for individuals with a diagnosis of BPD. Critically, the model highlights the fluid nature of autonomy in these individuals and how autonomy can be supported and upheld effectively. Participants described relational autonomy as a dynamic process involving relational skill building, having choice and involvement in care decisions, empathic staff and services and flexible and responsive services. Factors relating to ideal relational autonomy were fundamentally upheld by human rights and policy. It was recognised that relational autonomy was difficult to achieve and may be thought of as more of an end goal. Frequently, services and service users seemed to fall into forced or diminished autonomy where service users' capacity and abilities were assumed and they felt abandoned or where they felt overly reliant on services and professionals took autonomy away. This was influenced by factors relating to understanding and implementing rights, beliefs, attitudes and labelling, decision-making, the nature of BPD, risk, relationships with professionals and services and resources and performance.

In light of the dynamic nature of autonomy, it is hypothesised that 'edges of autonomy' hold parallels to BPD symptomology, such as common relational patterns of idealisation and devaluation (American Psychiatric Association, 2013) that may be characteristic of diminished and forced autonomy, respectively. 'Diminished autonomy' meant over-reliance on services, but service users may be more likely to feel 'held in mind' and in receipt of an idealised level of support form services. 'Forced autonomy' was considered to leave service users feeling abandoned and unsupported.

Appropriately named as 'relational autonomy', relationships, safety and containment were considered integral to promotion of autonomy in the theoretical model. In the literature, positive experiences of care have been linked to safe and containing therapeutic relationships and environments. Therapists who showed genuine interest and who were approachable and honest made their clients feel appreciated, listened to and understood. Staff who are considered unavailable, distant and judgemental meant clients were more likely to feel isolated, undeserving of support and criticised (Katsakou & Pistrang, 2018).

The current study and emerging theoretical model are informed by a HRBA. Fundamentally, human rights and policy were considered to underpin relational autonomy within the theoretical model. Mental health professionals described how rights-based approaches were comparable with their professional standards. The importance of embedding rights-based approaches into codes of practice is highlighted within the literature and can support mental health professionals to implement such approaches while holding individual professionals, their regulatory bodies and wider public services to account (Butchard & Greenhill, 2015; Kinderman & Butler, 2006).

Despite mental health professionals affiliating themselves with rights-based approaches, the qualitative data also identified a general lack of understanding as to how human rights could be implemented practically and upheld within a BPD service. Indeed, human rights-based approach frameworks have been criticised for containing vague ideas that are overly conceptual, difficult to define and implement (Butchard & Kinderman, 2019; Kinderman & Butler, 2006).

In relation to general attitudes and beliefs, the current study highlighted a general lack of understanding about the BPD diagnosis among some groups of mental health practitioners, an impression supported by published evidence (Dickens, Hallett, et al., 2016; Dickens, Lamont, et al., 2016). In the current study, negative beliefs and attitudes relating to the diagnosis of BPD often meant that service users felt invalidated and criticised, often by mental health professionals; also represented in published research (Chartonas et al., 2017; Deans & Meocevic, 2006; Lewis & Appleby, 1988; Woollaston & Hixenbaugh, 2008). It is important to acknowledge the impact of negative attitudes on the quality of care and service user experience, given that human rights may be directly impacted. In the current study beliefs, attitudes and the BPD label were key factors impinging ideal 'relational autonomy', leading to 'forced autonomy' or 'diminished autonomy'. The literature has further identified that negative attitudes impact negatively on care experiences (Deans & Meocevic, 2006; Forsyth, 2007; Katsakou & Pistrang, 2018), and that public bodies should be fulfilling their obligation to uphold human rights (Department of Health and Social Care, 2021).

Given the negative connotations associated with the BPD diagnosis identified in existing literature, and within the theoretical model, emphasising alternative constructs and practices may be more beneficial, and conducive to a human rights framework. The theoretical model may be a complementary adjunct to the Power Threat Meaning Framework (L Johnstone & Boyle, 2018) where constructs of mental health move away from diagnostic labels and towards understandable responses to trauma, early life adversity and acquired coping strategies.

Theory of planned behaviour (TPB; Ajzen, 1991) may offer a potential explanation as to the challenges posed by mental health professionals in implementing rights-based approaches highlighted in the current study. TPB proposes that for an individual to act and behave in a specific way, they must hold the intention to do so. Three underlying factors influence this intention: attitude, subjective norm and perceived behavioural control (Ajzen, 1991). In the context of the current study, negative attitudes towards a BPD diagnosis may influence intentions to uphold rights. Perceived subjective norms may influence how one should act and react to an individual with a BPD diagnosis. This is evident in the current findings were mental health practitioners working with the client group demonstrated positive attitudes but their counterparts working outside specialist services may operate in a working culture where negativity predominates, and rights are disenfranchised.

Consistent with national guidance (NICE, 2009), participants spoke of the importance of service users having choice when accessing mental health services and striving to ensure this is a collaborative process. Models of decision-making in healthcare have evolved from ideas of paternalism, towards autonomy and reciprocity (Pelto-Piri et al., 2013). In the current study it appears that some mental health professionals, particularly outside of specialist services, dominate the decision-making process and show limited collaboration with service users. Such paternalistic approaches assume a clinician ultimately made decisions about care and treatment, representative of 'diminished' autonomy in the theoretical model. Approaches to decision-making focused on autonomy assume decisions are made by the informed client. Although informed, such an approach may leave the client feeling unsupported, paralleling 'forced' autonomy in the theoretical model. Reciprocity is considered the ideal for shared decision-making and assumes there is mutual respect and collaboration where professionals work in partnership with service users to provide opportunity for active participation in mental health care and planning (Charles et al., 1999). Within the current study, mental health professionals described practices symbolic of reciprocity where they strived to work in partnership with service users, considered all decision-making to be shared and actively invited participation and coproduction in the planning and delivery of services.

Strengths and Limitations

This study addressed a gap in the research by exploring autonomy and impinging factors, within a specialist personality disorder service. Promotion of autonomy and recognition of imposing factors is important given the national guidance (NICE, 2009) and that individuals with BPD are likely to have experienced invalidating environments and relationships with caregivers that thwarted their capacity for autonomy and relatedness to others (Linehan, 1993; Ryan, 2005). A qualitative design gave voice to service users who may otherwise be disempowered, and the incorporation mental health professionals' views provided insight into the service context. A social constructionist approach to grounded theory enabled the understanding and interpretation of factors that supported mental health professionals and services to uphold relational autonomy and service user experience of such factors. The theoretical model highlights the precarious nature of relational autonomy, rather than placing blame on individual services or groups of professionals for perceived underperformance.

Despite the strength of this research, undoubtedly, autonomy is a complex phenomenon, evident in its presence in varied aspects of academic literature and national guidance. To provide context, each interviewee was provided with an accessible definition of autonomy and its relevance to human rights-based approaches. While each participant was asked about their understanding, prior to receiving definitions, information provided to them may have influenced their perspectives. Perceived challenges and lack of familiarity from participants' ability to define autonomy is important to consider when the term is frequently used in legislation, national guidance and human rights approaches.

The method of recruitment may have resulted in those with more ardent views about the BPD label, human rights, and autonomy volunteering to take part in the study. Service users who volunteered to take part were also known to services and would therefore have greater knowledge about mental health services and care. Recruiting from services negates the inclusion of those with a diagnosis of BPD, and individuals who know someone with the diagnosis (such as, informal carers and relatives) who have not sought help from secondary mental health services.

There were fewer service users recruited for the project, and there may be different reasons for this. The interviews were completed during the Covid-19 pandemic and conducted remotely. Participants did not have the opportunity to meet with the researcher in person, possibly increasing already felt anxiety at being a research participant; impacting their performance anxiety and ability to form social connection with the researcher. Anxiety related to virtual interviews may have been greater for service user participants who will undoubtedly experience apprehension in meeting new people given that a central feature of their difficulties involves forming interpersonal relationships. During the pandemic, it was widely documented that many professionals within a variety of health services were redeployed. This may have further impacted the resources available for service users' treatment and increased staffs stress and workload. Surprisingly, few participants raised issues pertaining to the pandemic, specifically how services, their treatment or the treatment offered was impacted. While the pandemic was not a significant consideration from participants in the current study, there may have been factors impacting mental health service performance and experience of accessing and offering services that was beyond their awareness or consideration.

It is possible that the use of the BPD label in advertising the project influenced recruitment of service users, and lower numbers compared to mental health practitioners. The use of the BPD label was carefully considered during the project's conception and the primary researcher consulted with Expert by Experiences about this. Expert groups reflected that utilising the term 'BPD" for research purposes could be beneficial if it helped create positive change in attitudes and if improvement in services could grow from an empirical investigation. Expert groups also acknowledged the use of the term BPD in mental health services and that it is a universal language that organises and structures access to services.

Clinical Implications

The current study highlights the importance of a robust service model; one that is structured yet flexible in its approach to offering compassionate service user treatment and ultimately fosters relational autonomy. This ideal may be hampered by limited resources, meaning that service users feel they do not receive the care and support they require. Limited resource has been found to impact service user autonomy (Pelto-Piri et al., 2013) and this was paralleled in the current study with service users placed on long waiting lists and reduced staffing levels impacting the availability of interventions.

The current study highlights the ongoing impact of negative attitudes towards those with a BPD diagnosis and anxiety associated at working with a high-risk client group. Findings suggest that when staff feel unsupported and lack compassionate understanding of the complex nature of client group, they may resort to more restrictive practices. Their own stilted professional autonomy will consequently impinge on service user autonomy and experience of a positive journey through mental health services.

Other research has demonstrated usefulness training interventions to improve knowledge and combat negative attitudes (Dickens, Hallett, et al., 2016; Institute of Mental Health, 2013; Lamph et al., 2014). While these training models will have some focus on the nature of BPD through a biopsychosocial lens, the current study's findings emphasise the importance of more detailed psychologically informed understanding and relational nature of BPD. According to the theoretical model, where there is a breakdown in the relationship between service users and mental health professional because the service user feels unheard and unsupported, they are likely to feel abandoned by services.

Trauma-informed care highlight the negative impact of services to those who have experienced adversity and trauma (Sweeney et al., 2016). There is often emphasis on reducing restrictive practices, including medical and physical restraint to prevent re-traumatisation (Care Quality Commission, 2017). However, trauma-informed approaches also emphasise how systemic and client-therapist power imbalances can also contribute to re-traumatisation. Findings in the current study highlight a narrative of thwarted autonomy and overpowering, invalidating and abusive relationships as being some of the contributary factors of BPD symptomology. Therefore, mental health professionals need to have concrete awareness of their impact of their relationships with service users and the impact of service performance and therapeutic relationships on their clients.

Specialist personality disorder services are well positioned to offer professional consultation to generic mental health services, particularly inpatient services. The theoretical model could go some way to support staff training programmes, including trauma-informed approaches to service delivery. Clinical psychology would be well positioned to utilise the theoretical model systemically with multidisciplinary teams to increase understanding of service and damaging factors contributing to ‘forced’ and ‘diminished autonomy’. The focus of psychological consultation would then turn to support in increasing the interactive factors contributing to ‘relational autonomy’; such as having robust therapeutic boundaries where service users feel supported and psychologically safe within the service and chosen intervention.

Expert knowledge and experience from working with a BPD client group will not only improve understanding but will, in turn, also improve service user experience and increase the likelihood of compassionate care approaches. Generic services may benefit from specific training on models of decision-making, such as those highlighted in Pelto-Piri et al. (2013) and how collaborative decision-making processes are integral to fostering autonomy.

The findings from the current study also highlight the need for staff support, particularly when working with a complex and high-risk client group. Compassionate leadership approaches will not only support staff and services but also have positive consequences for service users sense of compassion from organisations supporting them (West & Chowla, 2017).

Suggestions for future research

Following a qualitative enquiry of autonomy among service users with a diagnosis of BPD and the service response to uphold autonomy, further empirical investigation to test specific aspects of the theoretical model would be advantageous. Choice and involvement were captured under optimal relational autonomy within the theoretical model, with a lack of involvement in decision-making featured as a challenge to upholding autonomy. Honing in on specific models of decision-making through empirical investigation, such as those highlighted in Pelto-Piri et al. (2013), to capture the impact of perceived support and recovery from a service user perspective would proactively improve services and instruct methods of involved decision-making when considering treatment interventions.

The current study was conducted in the North of England in a geographical location where the population is predominantly White British, which is also reflected in the study's sample. It may be beneficial for a similar study to be repeated in other geographical regions that include both urban and rural locations. Such a design may yield a more diverse participant group and enable opportunity to explore additional cultural factors impacting autonomy. The literature highlights a narrative that may conceptualise 'autonomy' as inherently individualistic and a Western ideal. Individual autonomy risks ignoring the role of relationships and the need for connection with others to support decision-making (Dove et al., 2017). A focus on diversifying the participant pool may bring to light cultural differences in what someone desires in being an autonomous person and what additional support systems may nurture this.

Furthermore, the current study did not include relatives and carers of those with a diagnosis of BPD. Many mental health Trusts often have carer groups that provide bespoke support. Further qualitative research with relatives and carers may provide further insights into the challenges of autonomy with the service group and the role significant others play in this.

Conclusions

Autonomy is understood to be dynamic and based of a range of complex factors that those with a diagnosis of BPD experience. Supportive relationships, skill building, collaborative decision-making and empathic services are all integral to upholding the ideal of relational autonomy. However, the ideal of relational autonomy is precarious and subject to its own barriers and obstacles. Autonomy is not considered to lie within the individual which is highlighted through the inclusion of both service users and mental health professionals who each offer unique perspectives. The nature of difficulties in BPD are inherently relational and it is vital that services and staff are attuned to this, not only in formal therapeutic interventions, but for each individual interaction. When considering service design and provision, knowledge of decision-making models, trauma-informed approaches and a compassionate leadership stance will be key.

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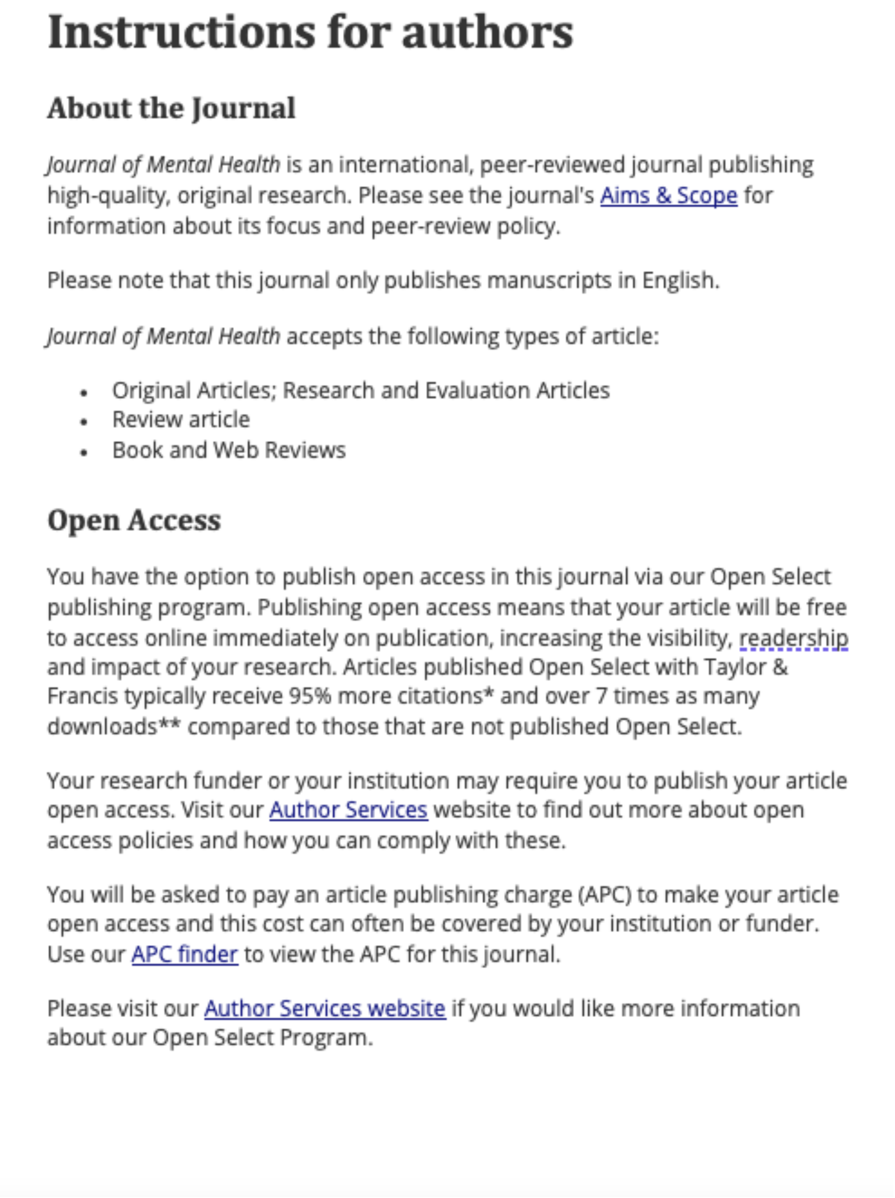
Appendices

Appendix 1: Manuscript Submission Guidelines: Journal of Mental Health



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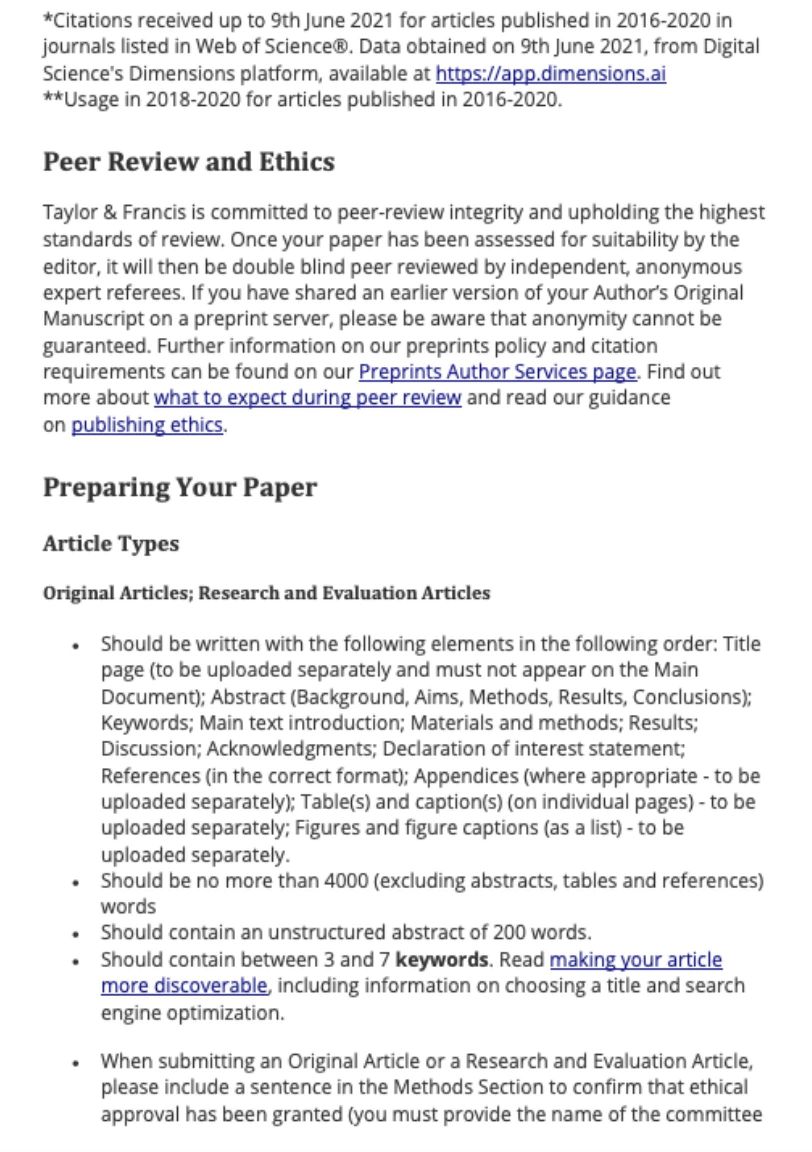

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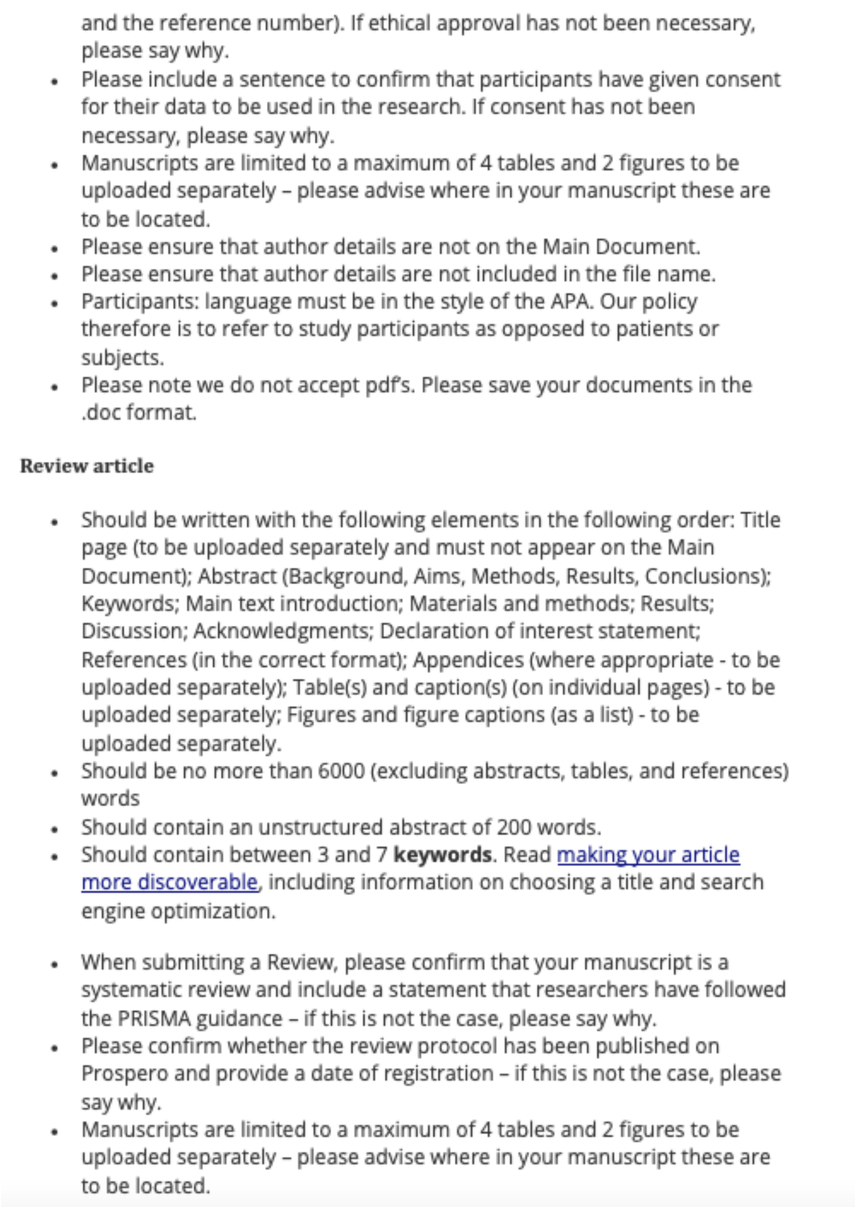

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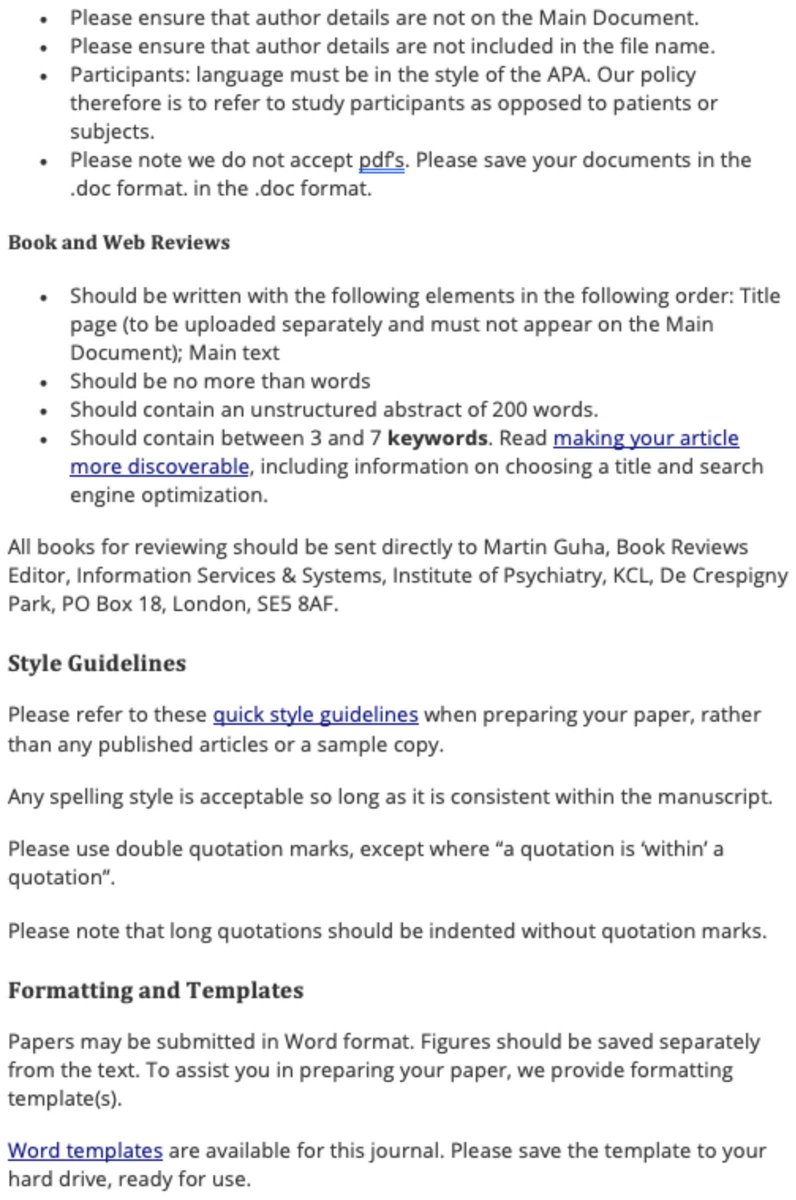

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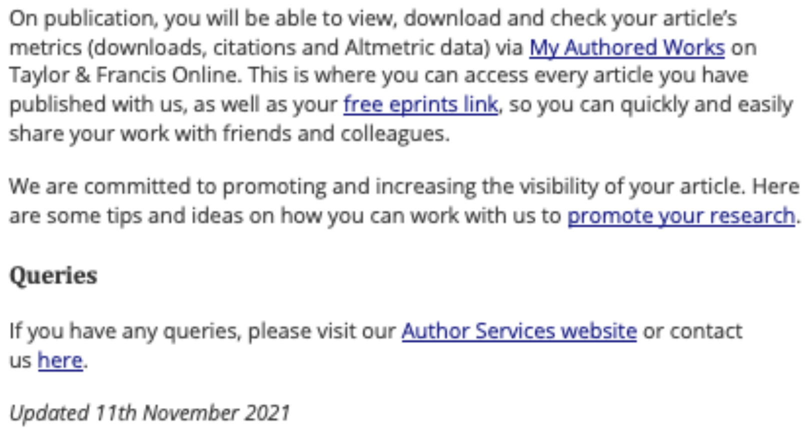

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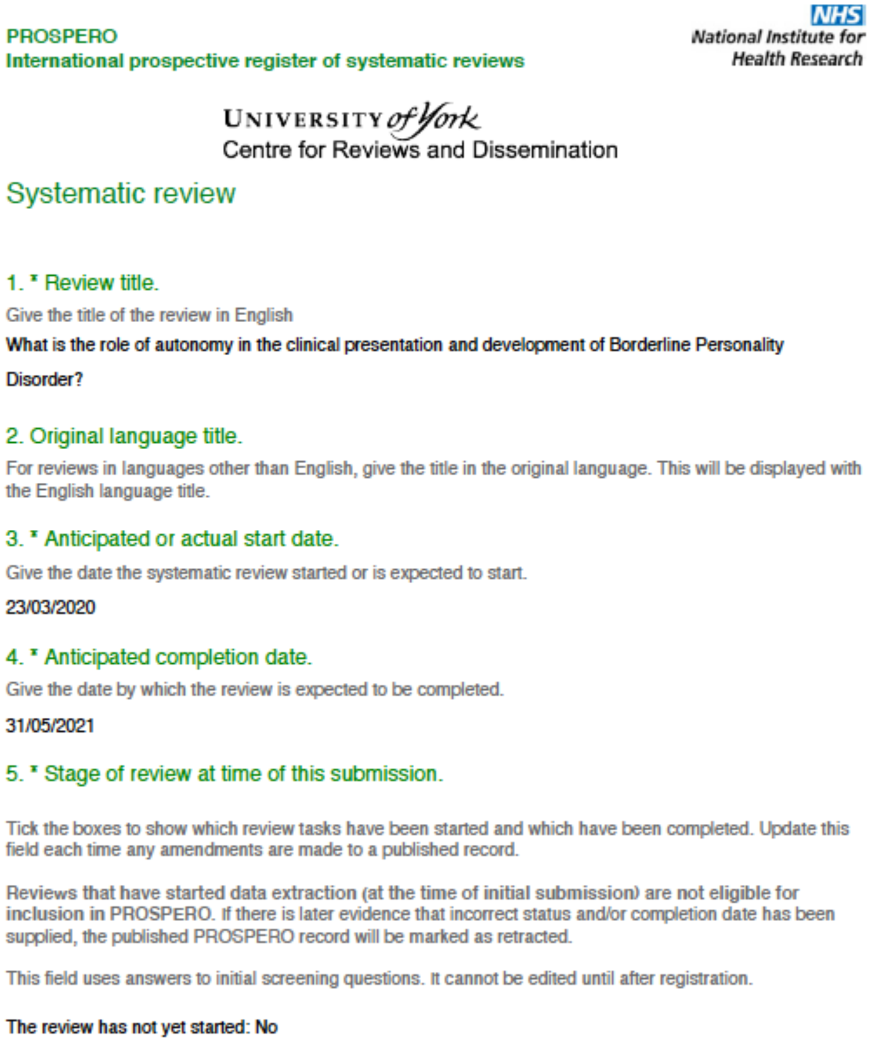
Queries

If you have any queries, please visit our Author Services website or contact us here.

Updated 11th November 2021

Appendix 2: Prospero Protocol



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

UNIVERSITY *of York*
Centre for Reviews and Dissemination

Systematic review

1. * Review title.

Give the title of the review in English

What is the role of autonomy in the clinical presentation and development of Borderline Personality Disorder?

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

23/03/2020

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

31/05/2021

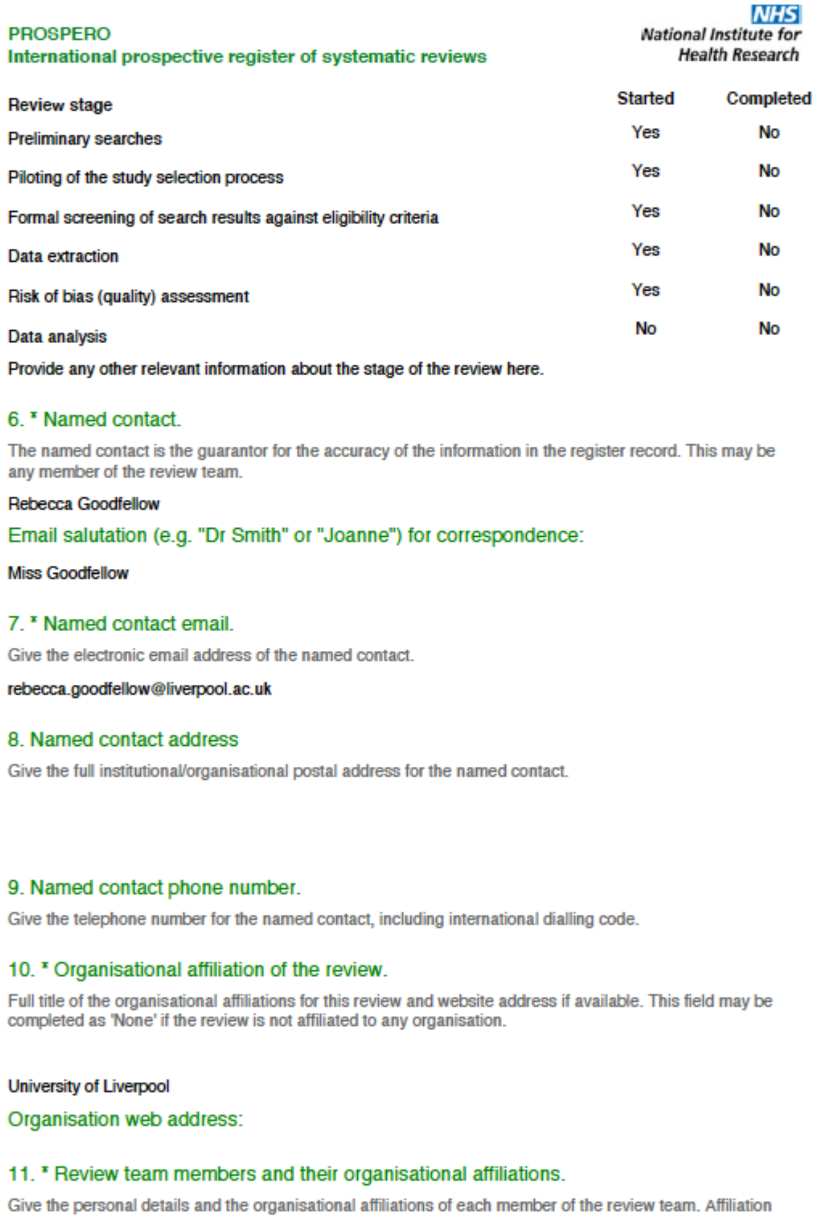
5. * Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.

Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.

This field uses answers to initial screening questions. It cannot be edited until after registration.

The review has not yet started: No



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Review stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	Yes	No
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	Yes	No
Risk of bias (quality) assessment	Yes	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Rebecca Goodfellow

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Miss Goodfellow

7. * Named contact email.

Give the electronic email address of the named contact.

rebecca.goodfellow@liverpool.ac.uk

8. Named contact address

Give the full institutional/organisational postal address for the named contact.

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

10. * Organisational affiliation of the review.

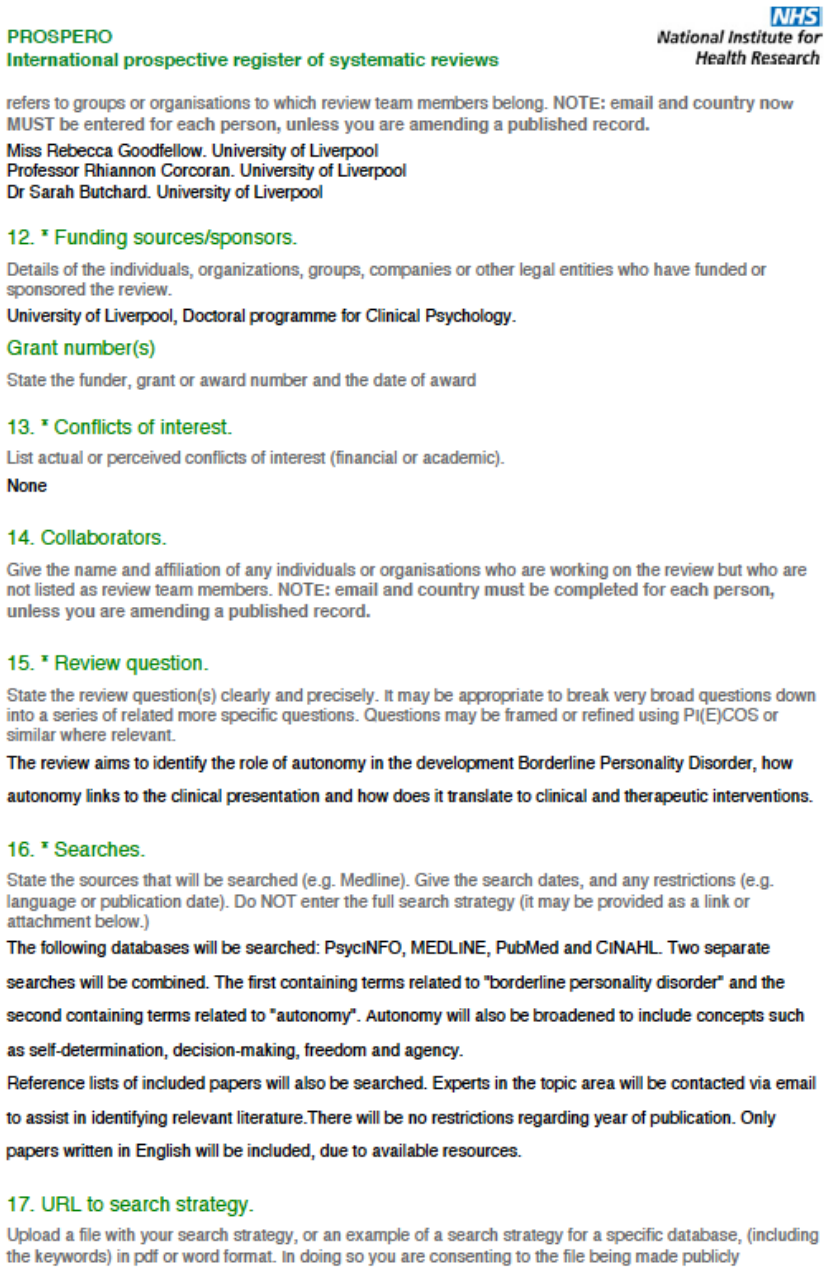
Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Liverpool

Organisation web address:

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation



refers to groups or organisations to which review team members belong. NOTE: **email and country now MUST be entered for each person, unless you are amending a published record.**

Miss Rebecca Goodfellow. University of Liverpool
Professor Rhiannon Corcoran. University of Liverpool
Dr Sarah Butchard. University of Liverpool

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

University of Liverpool, Doctoral programme for Clinical Psychology.

Grant number(s)

State the funder, grant or award number and the date of award

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. NOTE: **email and country must be completed for each person, unless you are amending a published record.**

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

The review aims to identify the role of autonomy in the development Borderline Personality Disorder, how autonomy links to the clinical presentation and how does it translate to clinical and therapeutic interventions.

16. * Searches.

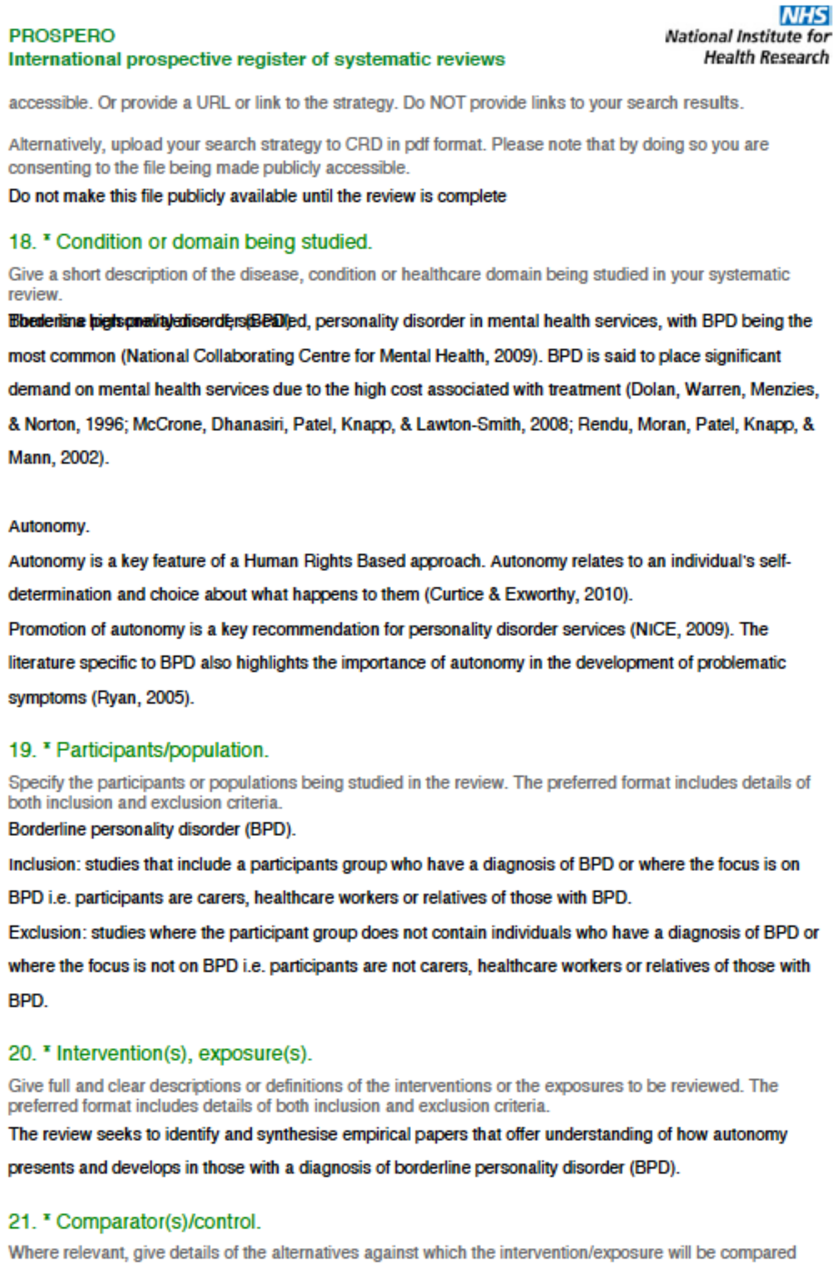
State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

The following databases will be searched: PsycINFO, MEDLINE, PubMed and CINAHL. Two separate searches will be combined. The first containing terms related to "borderline personality disorder" and the second containing terms related to "autonomy". Autonomy will also be broadened to include concepts such as self-determination, decision-making, freedom and agency.

Reference lists of included papers will also be searched. Experts in the topic area will be contacted via email to assist in identifying relevant literature.There will be no restrictions regarding year of publication. Only papers written in English will be included, due to available resources.

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly



accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search results.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Borderline personality disorder (BPD) [illegible]ed, personality disorder in mental health services, with BPD being the most common (National Collaborating Centre for Mental Health, 2009). BPD is said to place significant demand on mental health services due to the high cost associated with treatment (Dolan, Warren, Menzies, & Norton, 1996; McCrone, Dhanasiri, Patel, Knapp, & Lawton-Smith, 2008; Rendu, Moran, Patel, Knapp, & Mann, 2002).

Autonomy.

Autonomy is a key feature of a Human Rights Based approach. Autonomy relates to an individual's self-determination and choice about what happens to them (Curtice & Exworthy, 2010).

Promotion of autonomy is a key recommendation for personality disorder services (NICE, 2009). The literature specific to BPD also highlights the importance of autonomy in the development of problematic symptoms (Ryan, 2005).

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Borderline personality disorder (BPD).

Inclusion: studies that include a participants group who have a diagnosis of BPD or where the focus is on BPD i.e. participants are carers, healthcare workers or relatives of those with BPD.

Exclusion: studies where the participant group does not contain individuals who have a diagnosis of BPD or where the focus is not on BPD i.e. participants are not carers, healthcare workers or relatives of those with BPD.

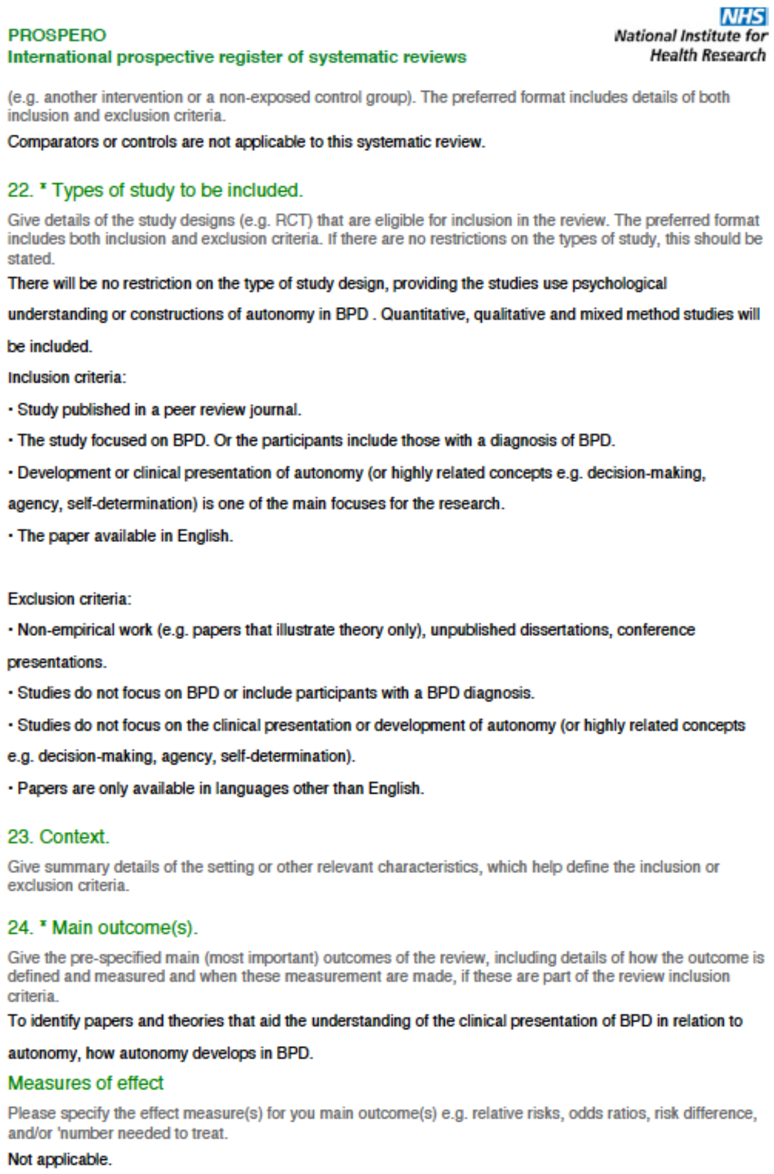
20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

The review seeks to identify and synthesise empirical papers that offer understanding of how autonomy presents and develops in those with a diagnosis of borderline personality disorder (BPD).

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared



(e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Comparators or controls are not applicable to this systematic review.

22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

There will be no restriction on the type of study design, providing the studies use psychological understanding or constructions of autonomy in BPD . Quantitative, qualitative and mixed method studies will be included.

Inclusion criteria:

- Study published in a peer review journal.
- The study focused on BPD. Or the participants include those with a diagnosis of BPD.
- Development or clinical presentation of autonomy (or highly related concepts e.g. decision-making, agency, self-determination) is one of the main focuses for the research.
- The paper available in English.

Exclusion criteria:

- Non-empirical work (e.g. papers that illustrate theory only), unpublished dissertations, conference presentations.
- Studies do not focus on BPD or include participants with a BPD diagnosis.
- Studies do not focus on the clinical presentation or development of autonomy (or highly related concepts e.g. decision-making, agency, self-determination).
- Papers are only available in languages other than English.

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

24. * Main outcome(s).

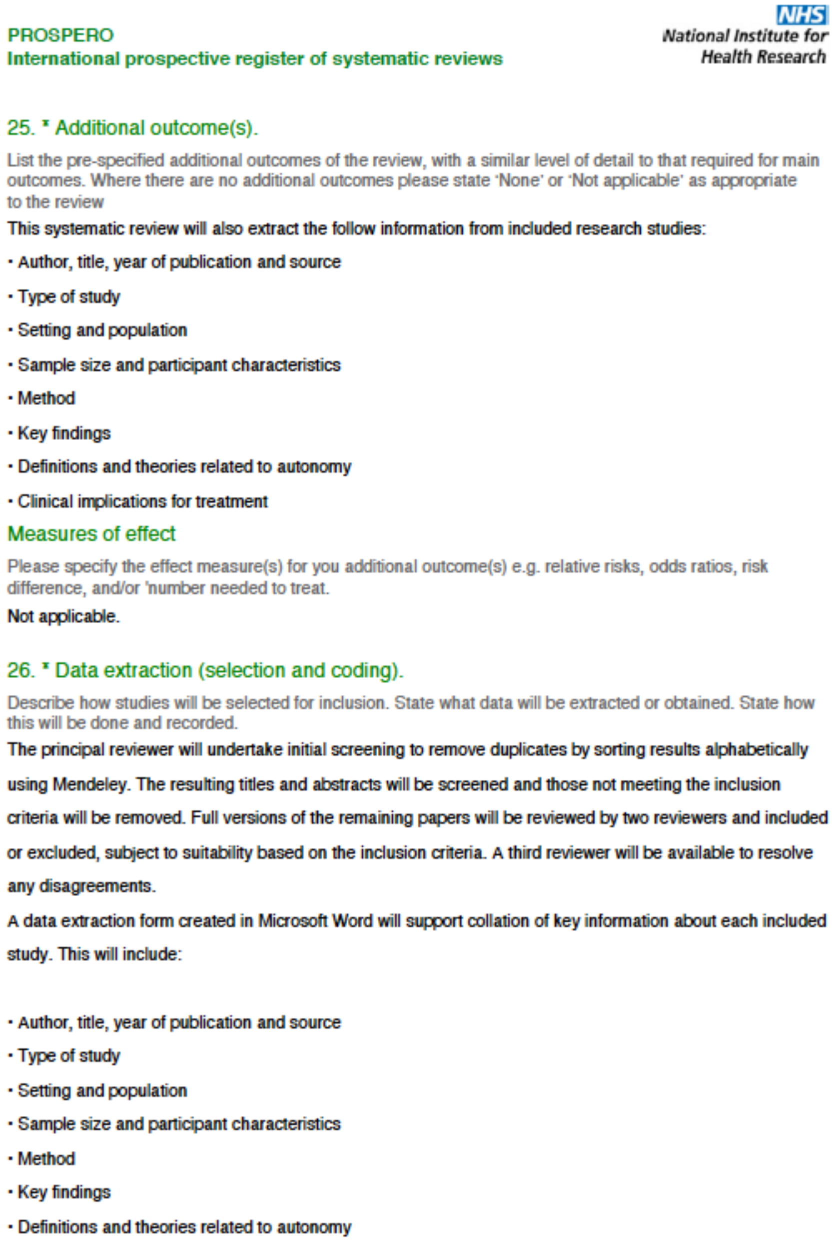
Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

To identify papers and theories that aid the understanding of the clinical presentation of BPD in relation to autonomy, how autonomy develops in BPD.

Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable.



25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

This systematic review will also extract the follow information from included research studies:

- Author, title, year of publication and source
- Type of study
- Setting and population
- Sample size and participant characteristics
- Method
- Key findings
- Definitions and theories related to autonomy
- Clinical implications for treatment

Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

The principal reviewer will undertake initial screening to remove duplicates by sorting results alphabetically using Mendeley. The resulting titles and abstracts will be screened and those not meeting the inclusion criteria will be removed. Full versions of the remaining papers will be reviewed by two reviewers and included or excluded, subject to suitability based on the inclusion criteria. A third reviewer will be available to resolve any disagreements.

A data extraction form created in Microsoft Word will support collation of key information about each included study. This will include:

- Author, title, year of publication and source
- Type of study
- Setting and population
- Sample size and participant characteristics
- Method
- Key findings
- Definitions and theories related to autonomy

- Clinical implications for treatment

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

The Mixed Methods Assessment Tool (MMAT) (Hong et al, 2018) will be used to assess for quality. MMAT is used for quantitative, qualitative and mixed method designs.

28. * Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This must not be generic text but should be specific to your review and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

Interpretations and explanations offered in the original studies related to development and clinical presentation of autonomy in BPD will be treated as data and used to produce a synthesis. A summary of included studies will be provided in narrative form and accompanied by a summary table.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

Not applicable.

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Living systematic review
No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

COVID-19
No

Crime and justice
No

Dental
No

Digestive system

No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
Yes

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

England

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

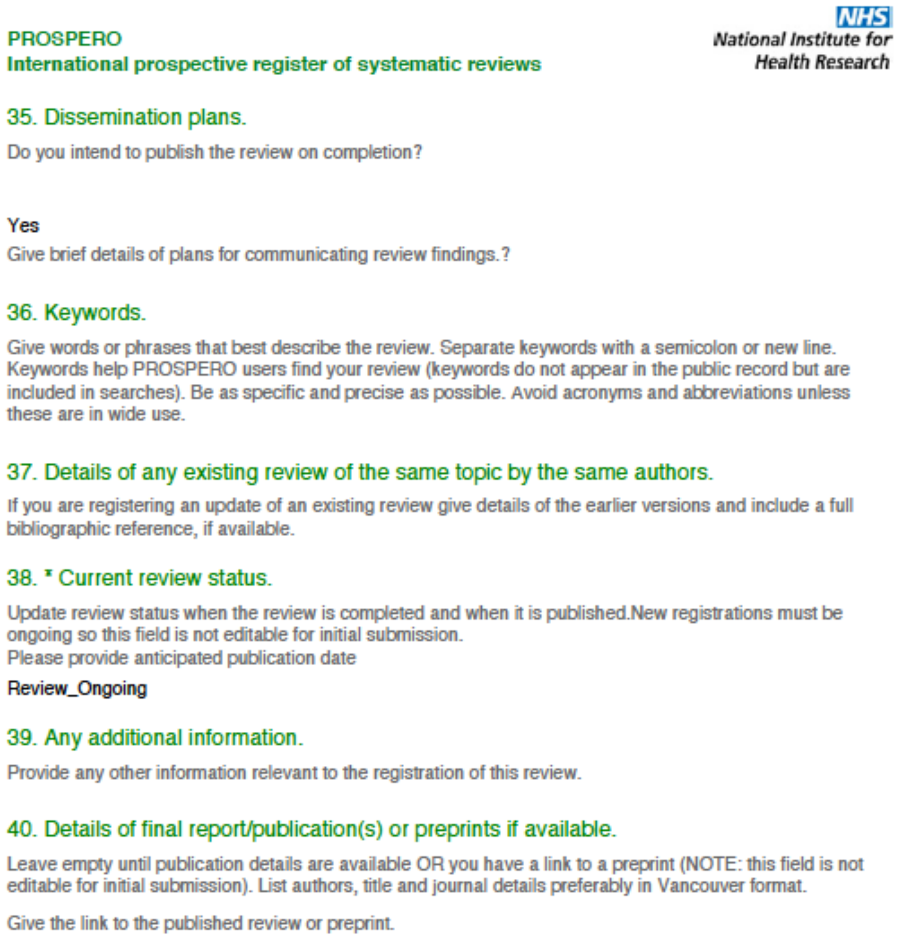
If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.



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35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.

Update review status when the review is completed and when it is published.New registrations must be ongoing so this field is not editable for initial submission.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.

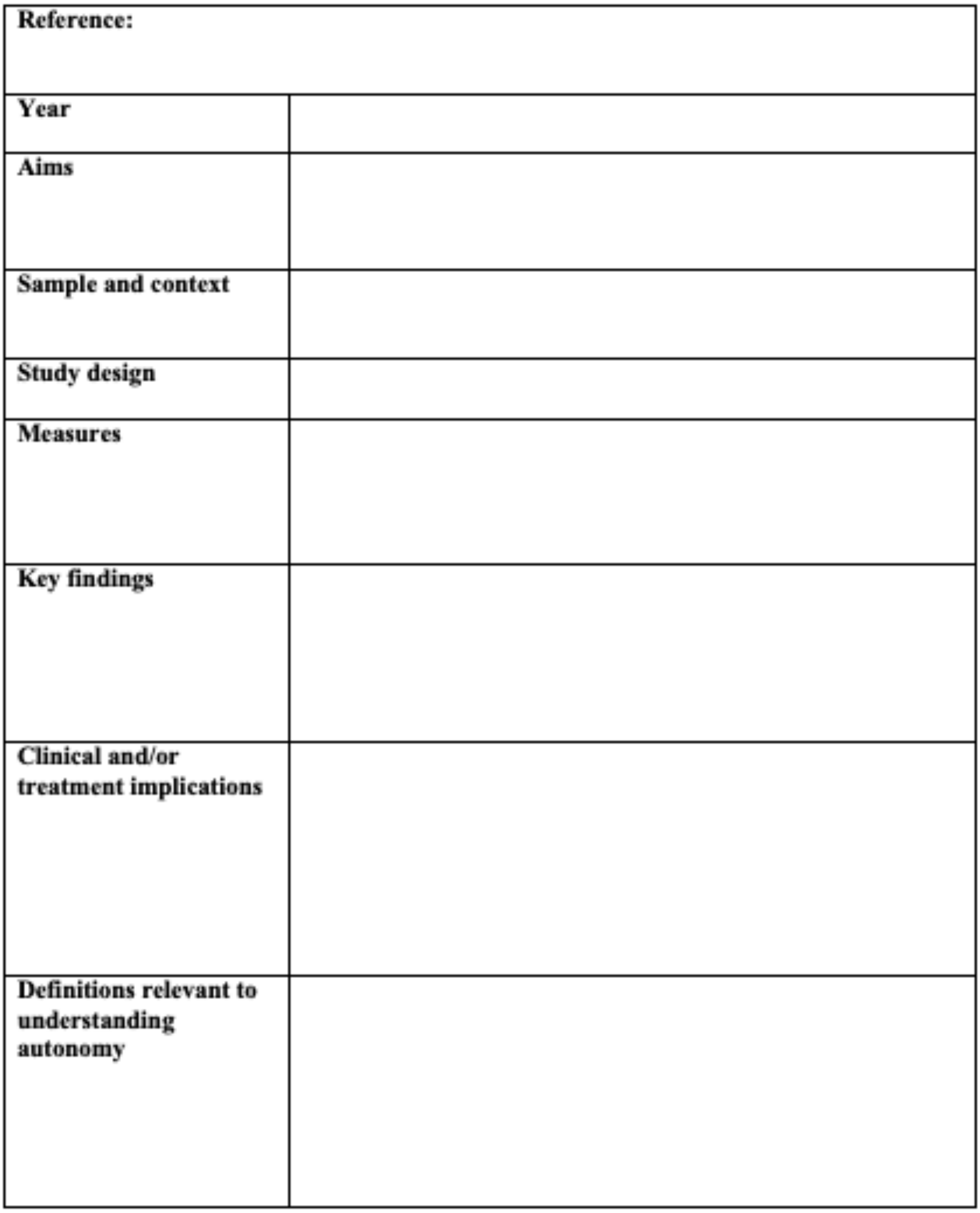
Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Give the link to the published review or preprint.

Appendix: 3: Mixed Methods Assessment Tool

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	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?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

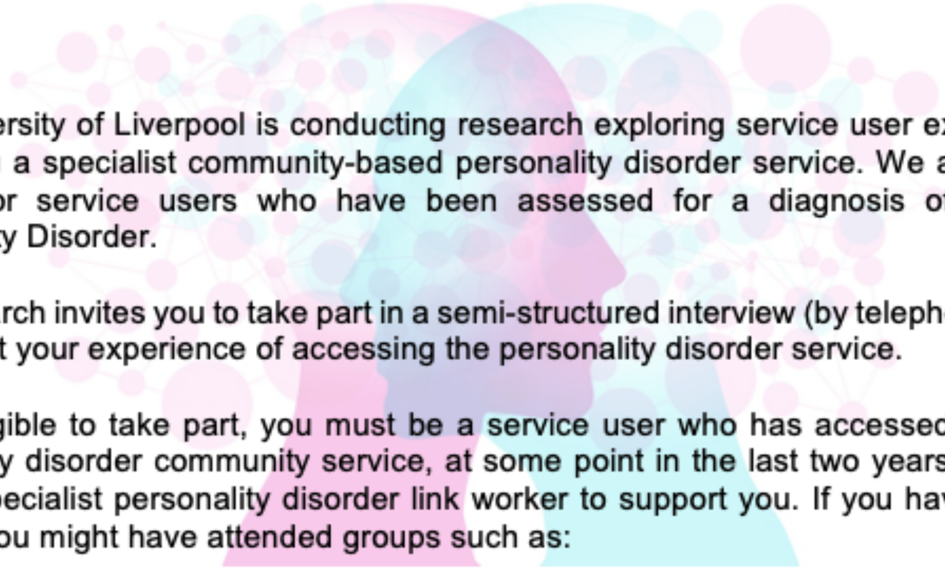
Appendix 4: Systematic Review Data Extraction Tool



Reference:	
Year	
Aims	
Sample and context	
Study design	
Measures	
Key findings	
Clinical and/or treatment implications	
Definitions relevant to understanding autonomy	

Appendix 5: Recruitment Poster

Understanding autonomy in a specialist community-based service for Borderline Personality Disorder: A grounded theory study.



The University of Liverpool is conducting research exploring service user experience of accessing a specialist community-based personality disorder service. We are currently looking for service users who have been assessed for a diagnosis of Borderline Personality Disorder.

The research invites you to take part in a semi-structured interview (by telephone or video call) about your experience of accessing the personality disorder service.

To be eligible to take part, you must be a service user who has accessed the Trust's personality disorder community service, at some point in the last two years. You might have a specialist personality disorder link worker to support you. If you have used this service, you might have attended groups such as:

Managing Emotions group,
Mentalization Based Therapy (MBT)
Dialectical Behaviour Therapy (DBT)

More detailed information is available, if you would like to know more about the research and what is involved. If you would like to take part or have any questions about the research and your eligibility to take part, please contact:

Rebecca Goodfellow (Trainee Clinical Psychologist)
07719419451
rebecca.goodfellow@liverpool.ac.uk

or
John Chiocchi (Highly Specialist Peer Support Worker)
john.chiocchi@[redacted].nhs.uk

Appendix 6: Participant Information Sheet (service user version)

Understanding autonomy in a specialist community-based service for Borderline Personality Disorder: A grounded theory study.

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and if you would like more information or if there is anything that you do not understand, feel free to ask questions. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Background and purpose of the study

As you may be aware, there has been a lot of research conducted into the experiences of people who have received a diagnosis of borderline personality disorder. However, there are still a lot of gaps in the research. The current study aims to explore people's experiences of accessing and using specialist community-based personality disorder services. The research will be informed by a Human Rights Based Approach, focusing specifically on your experience of autonomy when using services and receiving support.

The research project will gather information from both service users and mental health professionals. Information, from both perspectives, will be combined and used to develop an overall understanding of autonomy. It is hoped that this information will be used to help further understand service user experience and continue to develop services to inform more effective ways of working.

Why have I been chosen to take part?

You have been asked to take part in this study because you are currently, or previously, a service user of Trust's specialist community Personality Disorder service. Approximately five other service users will be taking part in the project and will meet the criteria for a diagnosis of Borderline Personality Disorder (also known as Emotionally Unstable Personality Disorder).

In addition to service users, approximately four staff members will be taking part in the research project.

Do I have to take part?

Participation in this study is voluntary and you are free to withdraw your consent and data, at any time. Declining the invitation to take part in the research, or withdrawal of consent, will have no impact on your current treatment or future access to services. If you agree to take part, you will be asked to sign a consent form.

What will happen if I take part?

If you choose to take part in the study, you will be invited for an interview, lasting approximately 60 to 90 minutes. You will be asked some questions relating to your experience of accessing and receiving support within the Trust's Personality Disorder Pathway service. There will be some structured questions to begin with, however, the interview will be a mostly conversational style. There are no right or wrong answers as the project is interested in your personal experiences and opinions. Therefore, each interview will be different and unique, depending on what participants say.

At some point during the interview, you will be given some further information to support you in answering some of the questions. This information will be the same for everyone and will be explained fully during the interview. You will be able to take this information away with you. The interview will take place with Rebecca Goodfellow (Trainee Clinical Psychologist). Interviews will be audio recorded and will take part at Trust premises, which will be an agreed location.

How will my data be used?
The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator (Rebecca Goodfellow) and Primary Project Supervisor (Professor Rhiannon Corcoran) acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to rebecca.goodfellow@liverpool.ac.uk or rhiannon.corcoran@liverpool.ac.uk Further information on how your data will be used can be found in the table below.

How will my data be collected?	The interview will be audio recorded using a Dictaphone. This recording will be transcribed to readable format.
How will my data be stored?	The transcription will be stored as an electronic file on a secure University computer, which is password protected.
How long will my data be stored for?	In accordance with University policy, your data will be stored for 10 years.
What measures are in place to protect the security and confidentiality of my data?	Transcription data and consent forms will be stored separately. Transcription data will be stored in a password protected electronic folder on a secure University computer system. Consent forms will be stored in a locked cabinet in the project supervisors office.
Will my data be anonymised?	All data will be anonymised and you will be allocated a pseudonym.
How will my data be used?	Your data will be used for a student thesis project for the University of Liverpool Clinical Psychology Doctorate programme. For this project, information from your interview will be used to identify commonly occurring themes. These themes and supporting quotes will be used in the final write-up of the thesis project. Following submission to the University, it is possible that the final results may be published in an academic journal. Please note, there will be no identifiable information used.
Who will have access to my data?	Only the primary researcher and project supervisors will have access to your data.
Will my data be archived for use in other research projects in the future?	Your anonymised data will be stored for a period of 10 years on a password protected computer at the University of Liverpool. Although it is unlikely to be used again, this means that your anonymised data is stored and available for use in future research projects.
How will my data be destroyed?	The electronic transcription data be deleted after 10 years. Signed consent forms will be shredded, and therefore, destroyed after 10 years.

Expenses and / or payments
Interviews will take place at an agreed location and on Trust premises. You will be reimbursed for your travel to and from the agreed interview location. You will be provided with information of how to claim your travel expenses from the University of Liverpool prior to your interview.

Are there any risks in taking part?
All participants are encouraged to speak freely, as all experiences and opinions are highly valued. While it is not anticipated that there will be any distress as a result of taking part in this study, it is acknowledged that some participants may wish to discuss some difficult and emotive topics. Therefore, it is important that you are supported before, during, and after the interview has taken place.

There may be an instance where you disclose information that raises concerns relating to your care, safety or wellbeing, or that of others. If this were to happen, the research team would encourage you to report this concern. We understand this may be a difficult thing to do. If you feel unable to report the concern, the research team has a duty of care to pass this information on to your allocated care team. This would only be in cases where a significant concern or risk was identified and would be discussed with you at the earliest opportunity.

For the above reason, it is important that only service users who are currently open to [redacted] mental health services will be included in this project. In order to check this, we will be asking which team you under and where you usually go for your appointments. In order the check that you are under the right team, and eligible to take part in the research, we will need to check which service you use. This means we will ask a clinician from your team, that you are still using that service. The clinician will not be informed about the data that you provide, and all your data will be anonymous.

Are there any benefits in taking part?
There are no direct benefits to taking part in this research. However, if you agree to take part, you will be providing valuable information to enable better understanding of service users and health care professionals within this specific type of service. Having a better understanding enables mental health professionals and services to provide optimum care to service users and may help to develop future services.

What will happen to the results of the study?
The results of the study will be used for a student project as part of the Clinical Psychology Doctorate Programme at the University of Liverpool. Overall themes and quotes from interviews will be used. Data will be anonymised, and you will be allocated a pseudonym. Only your age and gender will be used.

Following transcription of the interviews, each participant will be contacted to discuss and review their own transcript. Participants will also be invited to attend a focus group to feedback the overall research findings and themes. A presentation on research findings will be offered to the personality disorder pathway monthly governance meeting. Mental health professionals and Expert by Experience representatives regularly attend this meeting. Please note, that confidentiality of all participants will be upheld at all times. Following submission to the University, it is possible that the final results may be published in an academic journal.

What will happen if I want to stop taking part?
Participation is voluntary and you can withdraw from the study at any time during the study including during the interview and after the interview, without explanation. Should you wish to withdraw your data, please contact a member of the research team.

Please note, that it will not be possible to withdraw your data once the findings have been written up and submitted to the University for academic review. This is expected to be in April 2021.

What if I am unhappy or if there is a problem?
If you are unhappy, or if there is a problem, please feel free to let us know by contacting Rebecca Goodfellow (rebecca.goodfellow@liverpool.ac.uk or on 0151 794 5535) or Professor Rhiannon Corcoran (rhiannon.corcoran@liverpool.ac.uk 0151 794 5535) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

Who can I contact if I have further questions?
Please contact a member of the research team and we will do our best to help and answer any questions you may have.

Rebecca Goodfellow (Principle Investigator)
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John Chiocchi (Project Consultant)
Highly Specialist Carer and Peer Support Advisor
[redacted] NHS Foundation Trust
Integrated Governance Department
Equality, Diversity and Inclusion
[redacted]
Email: [redacted]
Tel [redacted]

Appendix 7: Participant Information Sheet (staff)

Understanding autonomy in a specialist community-based service for Borderline Personality Disorder: A grounded theory study.

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and if you would like more information or if there is anything that you do not understand, feel free to ask questions. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Background and purpose of the study

As you may be aware, there has been a lot of research conducted into the experiences of people who have received a diagnosis of borderline personality disorder. However, there are still a lot of gaps in the research. The current study aims to explore people's experiences of accessing and using specialist community-based personality disorder services. The research will be informed by a Human Rights Based Approach, focusing specifically on experiences of service user autonomy, and potential challenges for mental health professionals when offering support.

The research project will gather information from both service users and mental health professionals. Information, from both perspectives, will be combine and used to develop an overall understanding of autonomy. It is hoped that this information will be used to help further understand service user experience and continue to develop services to inform more effective ways of working.

Why have I been chosen to take part?

You have been asked to take part in this study because you are a mental health professional who currently works within the Trust Personality Disorder Pathway and are offering support to service users with a diagnosis of Borderline Personality Disorder (also known as Emotionally Unstable Personality Disorder). In order to check that you work within the correct team, and are therefore eligible to take part in this research, you will be asked some questions about your job title, job role and the location of your work place prior to taking part.

Approximately three other staff members will be taking part in the research. In addition to staff, approximately six service users (with a diagnosis of Borderline Personality Disorder or Emotionally Unstable Personality Disorder) will also be asked to take part.

Do I have to take part?

Participation in this study is voluntary and you are free to withdraw your consent and data, at any time. Declining the invitation to take part in the research, or withdrawal of consent, will have no impact on your current employment or future employment opportunities. If you agree to take part, you will be asked to sign a consent form.

What will happen if I take part?

If you choose to take part in the study, you will be invited for an interview, lasting approximately 60 to 90 minutes. You will be asked some questions relating to your experience of working within the Trust's Personality Disorder Pathway and offering support to service users. There will be some structured questions to begin with, however, the interview will be a mostly conversational style. There are no right or wrong answers as the project is interested in your personal experiences and opinions. Therefore, each interview will be different and unique, depending on what participants say.

During the interview, you will be given some further information to support you in answering some of the questions. This information will be the same for everyone and will be explained fully during the interview. You will be able to take this information away with you. The interview will take place with

Rebecca Goodfellow (Trainee Clinical Psychologist). Interviews will be audio recorded and will take part at Trust premises, which will be an agreed location.

How will my data be used?
The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of advancing education, learning and research for the public benefit.

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How will my data be collected?	The interview will be audio recorded using a Dictaphone. This recording will be transcribed to readable format.
How will my data be stored?	The transcription will be stored as an electronic file on a secure University computer, which is password protected.
How long will my data be stored for?	In accordance with University policy, your data will be stored for 10 years.
What measures are in place to protect the security and confidentiality of my data?	Transcription data and consent forms will be stored separately. Transcription data will be stored in a password protected electronic folder on a secure University computer system. Consent forms will be stored in a locked cabinet in the project supervisors office.
Will my data be anonymised?	All data will be anonymised and you will be allocated a pseudonym.
How will my data be used?	Your data will be used for a student thesis project for the University of Liverpool Clinical Psychology Doctorate programme. For this project, information from your interview will be used to identify commonly occurring themes. These themes and supporting quotes will be used in the final write-up of the thesis project. Following submission to the University, it is possible that the final results may be published in an academic journal. Please note, there will be no identifiable information used.
Who will have access to my data?	Only the primary researcher and project supervisors will have access to your data.
Will my data be archived for use in other research projects in the future?	Your anonymised data will be stored for a period of 10 years on a password protected computer at the University of Liverpool. Although it is unlikely to be used again, this means that your anonymised data is stored and available for use in future research projects.
How will my data be destroyed?	The electronic transcription data be deleted after 10 years. Signed consent forms will be shredded, and therefore, destroyed after 10 years.

Expenses and / or payments
Interviews will take place at an agreed location and on Trust premises. Staff members will not be reimbursed for their travel expenses, as interviews are expected to take place during working hours. Staff are encouraged to claim expenses through their own Trust expenses system.

Are there any risks in taking part?
All participants are encouraged to speak freely, as all experiences and opinions are highly valued. While it is not anticipated that there will be any distress as a result of taking part in this study, it is acknowledged that some participants may wish to discuss some difficult and emotive topics. Therefore, it is important that you are supported before, during, and after the interview has taken place. Should you be distressed and have ongoing concerns related to your own health and wellbeing, we would

encourage you to seek support from the Trust's Occupational Health Department or make an appointment to see your GP.

There may be a time where you disclose information that raises concerns relating to the care and safety of service users, and/ or their carers. In these cases, the research team would offer support in helping you report or raise concerns. We understand this may be a difficult thing to do. If you feel unable to report the concern, the research team has a duty of care to pass this information on to the service users allocated care team, or service it relates to. This would only be in cases where a significant concern or risk was identified and would be discussed with you at the earliest opportunity.

Are there any benefits in taking part?
There are no direct benefits to taking part in this research. However, if you agree to take part, you will be providing valuable information to enable better understanding of service users and health care professionals within this specific type of service. Having a better understanding enables mental health professionals and services to provide optimum care to service users and may help to develop future services.

What will happen to the results of the study?
The results of the study will be used for a student project as part of the Clinical Psychology Doctorate Programme at the University of Liverpool. Overall themes and quotes from interviews will be used. Data will be anonymised, and you will be allocated a pseudonym. Only your age and gender will be used.

Following transcription of the interviews, each participant will be contacted to discuss and review their own transcript. Participants will also be invited to attend a focus group to feedback the overall research findings and themes. A presentation on research findings will be offered to the personality disorder pathway monthly governance meeting. Mental health professionals and Expert by Experience representatives regularly attend this meeting. Please note, that confidentiality of all participants will be upheld at all times. Following submission to the University, it is possible that the final results may be published in an academic journal.

What will happen if I want to stop taking part?
Participation is voluntary and you can withdraw from the study at any time during the study including during the interview and after the interview, without explanation. Should you wish to withdraw your data, please contact a member of the research team.

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Who can I contact if I have further questions?
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Tel: 0151 794 5534

Professor Rhiannon Corcoran (Primary Project Supervisor)
Professor of Psychology and Public Mental Health
Psychological Sciences
Institute of Psychology Health and Society
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Dr Sarah Butchard (Secondary Project Supervisor)
Senior Academic Tutor
Doctorate in Clinical Psychology Programme
The University of Liverpool
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Tel: 0151 794 5534

John Chiocchi (Project Consultant)
Highly Specialist Carer and Peer Support Advisor
[redacted]
Integrated Governance Department
[redacted]
Email: [redacted]
Tel: [redacted]

Appendix 8: Interview schedule and rationale

All participants will be encouraged to talk freely about their experience of using services. to support the facilitation of the interview, and gain rich data, it is anticipated that some participants will require prompt questions.

It is anticipated that participants will have limited understanding of a human rights-based approach, as the NHS trust does not actively adopt the model. However, the Trust will undoubtedly be promoting rights unconsciously through other policy. For example, attempts to provide fair treatment through different modes of intervention (i.e. DBT, MBT and structured clinical management) where the time scales and number of clinical contacts are equal. Therefore, it is important to know what participants knowledge and understanding of human rights-based approach it and how this applies to mental health services. Participants will be offered the same HRBA information and then asked to comment on this. For example, what rights are most important to them and their experience of services upholding and promoting autonomy. Questions below are broad and flexible. Questions have been developed based on the researchers' knowledge of the service and what processes service users and staff experience and are exposed to during assessment and intervention stages.

Interview schedule: example key questions (numbered) with prompts.

Service user interviews:

1. What is your understanding of human rights and how this applies to you in your care and access to services?
    a. Is this topic something you have thought about previously?
    b. Have you any initial thoughts on this?
    c. What does this topic make you think of?

2. (*Participants given explanation of HRBA, autonomy and the FREDA principles*) What does this information mean for you?
    a. Is this new information to you?
    b. Does this information alter your opinion in any way?
    c. Does this information aid your understanding?

   d. Is there anything else that would be helpful to know?
   e. Are you curious for more information?
   f. Do you think discussing autonomy and a HRBA will be helpful?
   g. Does exploring autonomy seem an appropriate topic?
   h. Is autonomy and freedom of choice something that is important to you?
   i. How might autonomy be important in accessing services?

3. What is your experience of being autonomous in accessing and using the service?
   a. How were you referred to the service?
   b. What was your experience of being referred and assessed? (both positive and negative aspects)
   c. What are your experiences of treatment within the service?
   d. Do you feel you are given free choice in treatment options?
   e. What impacts your choice in treatment?
   f. What is your understanding about how treatment decisions are made?
   g. Does your level of autonomy change or stay the same? Why do you think this is?
   h. What are your experiences of being in crisis and accessing help?

4. How do you feel autonomy is upheld and promoted within the service?
   a. Can you tell me about your experience of how treatment decisions were made?
   b. Did you feel included in making decisions about your treatment?
   c. Did the service offer any additional options to become involved in making decisions about your care?
   d. Can you identify any ways the service ensured you were treated fairly?
   e. Can you give an example of how the service made you feel autonomous?
   f. Can you give an example of when you did not feel autonomous in accessing help or treatment?

5. Is there a way the service could further uphold and promote your individual experience of autonomy?
   a. What are the good or positive aspects about the service?
   b. How would you like to see the service improve?
   c. How could things be done differently?

    d. If you were to design the service that was certain to promote autonomy, what would you like to include?

Staff interviews:

1. What is your understanding of human rights and how this applies to healthcare?
    a. How do HRBA apply to the service you work in and support that is offered?
    b. Is this topic something you have thought about previously?
    c. Have you any initial thoughts on this?
    d. What does this topic make you think of?

2. (*Participants given explanation of HRBA and FREDA principles*) What does this information mean for you?
    a. Is this new information to you?
    b. Have you had any training on HRBA approaches previously?
    c. Does this information alter your opinion in any way?
    d. Does this information aid your understanding?
    e. Is there anything else that would be helpful to know?
    f. Are you curious for more information?
    g. Do you think discussing autonomy within a HRBA will be helpful?
    h. How do you think autonomy and HBRA apply to healthcare?
    i. Does exploring autonomy seem an appropriate topic?
    j. Is autonomy and freedom of choice something that is important to you?
    k. How might autonomy be important?
    l. Is promoting autonomy important for you when working with service users?

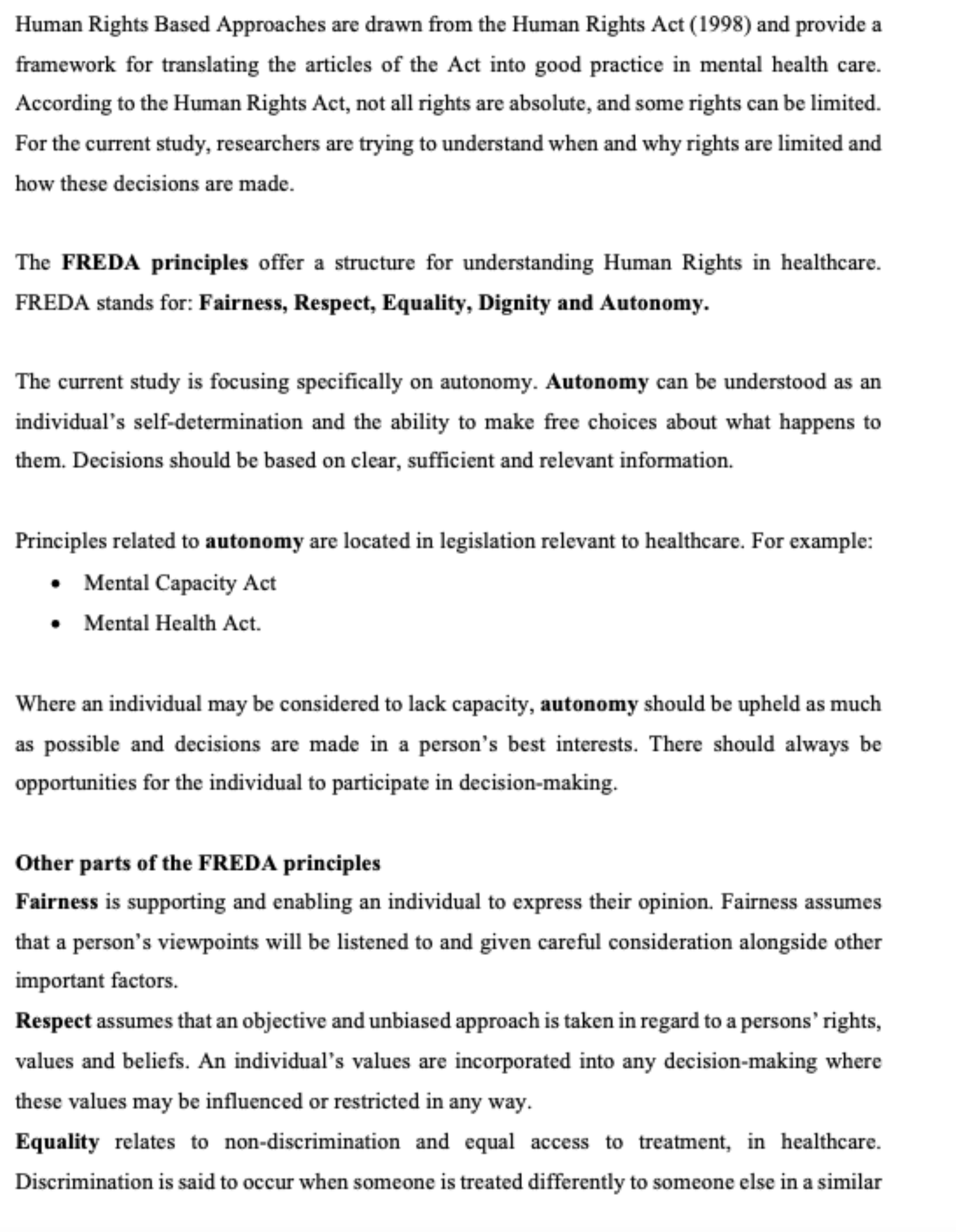
3. How do you feel autonomy is upheld and promoted with the service?
    a. Is autonomy an important aspect of care and treatment?
    b. Is the service designed to promote autonomy?
    c. What was your experience of people being referred and assessing the service? (both positive and negative aspects)
    d. What have you experienced when assessing people?
    e. What are your experiences of offering or referring for treatment within the service?

   f. How are decisions made about treatment?
   g. How are service users included in decision-making about treatment? Is there anything that gets in the way of this?
   h. What is your understanding about how treatment decisions are made?
   i. Do you think that service users feel autonomous and have free choice in accessing the service and making decisions about their treatment?
   j. Can you talk about some of your experiences of working with service users in this service and how autonomy might have been a factor?

4. How autonomous do you feel as a practitioner? What factors impact on this?
   a. Do you feel autonomous in your own practice and what you are able to offer service users?
   b. Does your sense of how autonomous you feel change or stay the same? What influences this?
   c. Can you think of an example of when you have tried to promote service user autonomy?
   d. Can you think of an example of when it has been difficult to promote and uphold autonomy for service users? What influences this?
   e. What are the barriers to offering an effective service?
   f. How is the promotion of autonomy similar or dissimilar to your core professional principles?

5. Is there a way the service could further uphold and promote individual service user experience of autonomy?
   a. What are the good or positive aspects about the service?
   b. How would you like to see the service improve?
   c. How could things be done differently?
   d. What are the barriers to implementing autonomy as a FREDA principle?
   e. If you were to design the service that were certain to promote, what would you like to include?

Appendix 9: Human Rights Based Approaches: Information for Participants



Human Rights Based Approaches are drawn from the Human Rights Act (1998) and provide a framework for translating the articles of the Act into good practice in mental health care. According to the Human Rights Act, not all rights are absolute, and some rights can be limited. For the current study, researchers are trying to understand when and why rights are limited and how these decisions are made.

The **FREDA principles** offer a structure for understanding Human Rights in healthcare. FREDA stands for: **Fairness, Respect, Equality, Dignity and Autonomy.**

The current study is focusing specifically on autonomy. **Autonomy** can be understood as an individual's self-determination and the ability to make free choices about what happens to them. Decisions should be based on clear, sufficient and relevant information.

Principles related to **autonomy** are located in legislation relevant to healthcare. For example:

- Mental Capacity Act
- Mental Health Act.

Where an individual may be considered to lack capacity, **autonomy** should be upheld as much as possible and decisions are made in a person's best interests. There should always be opportunities for the individual to participate in decision-making.

Other parts of the FREDA principles

Fairness is supporting and enabling an individual to express their opinion. Fairness assumes that a person's viewpoints will be listened to and given careful consideration alongside other important factors.

Respect assumes that an objective and unbiased approach is taken in regard to a persons' rights, values and beliefs. An individual's values are incorporated into any decision-making where these values may be influenced or restricted in any way.

Equality relates to non-discrimination and equal access to treatment, in healthcare. Discrimination is said to occur when someone is treated differently to someone else in a similar situation. Discrimination my also occur when people are treated the same, despite being in very different circumstances.

Dignity can be defined as a state or manner worthy of self-esteem and self-respect. In healthcare, this means that care and treatment offered should be aimed at promoting and supporting and individual's dignity and self-respect. Practices in healthcare should not undermine the fundamental aspects of a person's self-worth.

Human Rights Articles

- Article 2: The right to life
- Article 3: The right not to be tortured or treated in an inhuman or degrading way
- Article 4: The right to be free from slavery or forced labour
- Article 5: The right to liberty
- Article 6: The right to a fair trial
- Article 7: The right to no punishment without law
- Article 8: The right to respect for private and family life, home and correspondence
- Article 9: The right to freedom of thought, conscience and religion
- Article 10: The right to freedom of expression
- Article 11: The right to freedom of assembly and association
- Article 12: The right to marry and found a family
- Article 14: The right not to be discriminated against in relation to any of the rights contained in the European Convention

Articles most relevant to healthcare:

- The right to life.
- The right not to be tortured or treated in an inhuman or degrading way.
- The right to liberty.
- The right to respect for private and family life, home and correspondence.

Absolute rights include:

- Article 2: The right to life (is absolute in health care)
- Article 3: The right not to be tortured or treated in an inhuman or degrading way
- Article 4 (1) The right to be free from slavery
- Article 4 (2): The right to be free from forced labour

- Article 7: No punishment without law

The information in this document is adapted from:
Curtice, M. J., & Exworthy, T. (2010). FREDA: a human rights-based approach to healthcare. *The Psychiatrist*, *34*(4), 150-156.

This article is freely available. If you wish to have more information and read the article, please ask the researcher.

Appendix 10: Updated Interview Schedule

All participants will be encouraged to talk freely about their experience of using services. to support the facilitation of the interview, and gain rich data, it is anticipated that some participants will require prompt questions.

It is anticipated that participants will have limited understanding of a human rights-based approach, as the NHS trust does not actively adopt the model. However, the Trust will undoubtedly be promoting rights unconsciously through other policy. For example, attempts to provide fair treatment through different modes of intervention (i.e. DBT, MBT and structured clinical management) where the time scales and number of clinical contacts are equal. Therefore, it is important to know what participants knowledge and understanding of human rights-based approach it and how this applies to mental health services. Participants will be offered the same HRBA information and then asked to comment on this. For example, what rights are most important to them and their experience of services upholding and promoting autonomy. Questions below are broad and flexible. Questions have been developed based on the researchers' knowledge of the service and what processes service users and staff experience and are exposed to during assessment and intervention stages.

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Service user interviews:

1. What is your understanding of human rights and how this applies to you in your care and access to services?
    a. Is this topic something you have thought about previously?
    b. Have you any initial thoughts on this?
    c. What does this topic make you think of?

2. (*Participants given explanation of HRBA, autonomy and the FREDA principles*) What does this information mean for you?
    a. Is this new information to you?
    b. Does this information alter your opinion in any way?
    c. Does this information aid your understanding?
    d. Is there anything else that would be helpful to know?

    e. Are you curious for more information?
    f. Do you think discussing autonomy and a HRBA will be helpful?
    g. Does exploring autonomy seem an appropriate topic?
    h. Is autonomy and freedom of choice something that is important to you?
    i. How might autonomy be important in accessing services?

3. Why do you think autonomy important to consider for people with a diagnosis of Borderline Personality Disorder? (New questions based on theoretical sampling)
    a. What reflections do you have about your own autonomy? Is it a problem/difficult?
    b. Why do you think autonomy might be something to focus on for those with a BPD diagnosis?
    c. What challenges do you face in relation to your own autonomy?
    d. How do you think autonomy is impacted in BPD?
    e. Why do you think services might focus on upholding autonomy? And why specifically for BPD?
    f. Why do you think it is important to uphold autonomy for individuals?
    g. Why do you think it is important to uphold autonomy for people in mental health services?
    h. Why do you think it is important to uphold autonomy specifically for people with BPD?

4. What is your experience of being autonomous in accessing and using the service?
    a. How were you referred to the service?
    b. What was your experience of being referred and assessed? (both positive and negative aspects)
    c. What are your experiences of treatment within the service?
    d. Do you feel you are given free choice in treatment options?
    e. What impacts your choice in treatment?
    f. What is your understanding about how treatment decisions are made?
    g. Does your level of autonomy change or stay the same? Why do you think this is?
    h. What are your experiences of being in crisis and accessing help?

5. How do you feel autonomy is upheld and promoted within the service?
    a. Can you tell me about your experience of how treatment decisions were made?
    b. Did you feel included in making decisions about your treatment?
    c. Did the service offer any additional options to become involved in making decisions about your care?
    d. Can you identify any ways the service ensured you were treated fairly?
    e. Can you give an example of how the service made you feel autonomous?
    f. Can you give an example of when you did not feel autonomous in accessing help or treatment?

6. Is there a way the service could further uphold and promote your individual experience of autonomy?
    a. What are the good or positive aspects about the service?
    b. How would you like to see the service improve?
    c. How could things be done differently?
    d. If you were to design the service that was certain to promote autonomy, what would you like to include?

Staff interviews:

1. What is your understanding of human rights and how this applies to healthcare?
    a. How do HRBA apply to the service you work in and support that is offered?
    b. Is this topic something you have thought about previously?
    c. Have you any initial thoughts on this?
    d. What does this topic make you think of?

2. (*Participants given explanation of HRBA and FREDA principles*) What does this information mean for you?
    a. Is this new information to you?
    b. Have you had any training on HRBA approaches previously?
    c. Does this information alter your opinion in any way?
    d. Does this information aid your understanding?
    e. Is there anything else that would be helpful to know?
    f. Are you curious for more information?

g. Do you think discussing autonomy within a HRBA will be helpful?
h. How do you think autonomy and HBRA apply to healthcare?
i. Does exploring autonomy seem an appropriate topic?
j. Is autonomy and freedom of choice something that is important to you?
k. How might autonomy be important?
l. Is promoting autonomy important for you when working with service users?

3. Why is autonomy important to consider when working with people with a diagnosis of Borderline Personality Disorder? (New questions based on theoretical sampling)
    a. How do you think autonomy is impacted in BPD?
    b. Why do you think services might focus on upholding autonomy? And why specifically for BPD?
    c. Why do you think it is important to uphold autonomy for individuals?
    d. Why do you think it is important to uphold autonomy for people in mental health services?
    e. Why do you think it is important to uphold autonomy specifically for people with BPD?
    f. Why would autonomy be a problem for BPD?

4. How do you feel autonomy is upheld and promoted with the service?
    a. Is autonomy an important aspect of care and treatment?
    b. Is the service designed to promote autonomy?
    c. What was your experience of people being referred and assessing the service? (both positive and negative aspects)
    d. What have you experienced when assessing people?
    e. What are your experiences of offering or referring for treatment within the service?
    f. How are decisions made about treatment?
    g. How are service users included in decision-making about treatment? Is there anything that gets in the way of this?
    h. What is your understanding about how treatment decisions are made?

i. Do you think that service users feel autonomous and have free choice in accessing the service and making decisions about their treatment?
j. Can you talk about some of your experiences of working with service users in this service and how autonomy might have been a factor?

5. How autonomous do you feel as a practitioner? What factors impact on this?
    a. Do you feel autonomous in your own practice and what you are able to offer service users?
    b. Does your sense of how autonomous you feel change or stay the same? What influences this?
    c. Can you think of an example of when you have tried to promote service user autonomy?
    d. Can you think of an example of when it has been difficult to promote and uphold autonomy for service users? What influences this?
    e. What are the barriers to offering an effective service?
    f. How is the promotion of autonomy similar or dissimilar to your core professional principles?

6. Is there a way the service could further uphold and promote individual service user experience of autonomy?
    a. What are the good or positive aspects about the service?
    b. How would you like to see the service improve?
    c. How could things be done differently?
    d. What are the barriers to implementing autonomy as a FREDA principle?
    e. If you were to design the service that were certain to promote, what would you like to include?

Appendix 11: Narrative summary of interview (service user)

This interview was the fourth interview with a service user. Human rights to him meant being treated equally. He mentioned having been in a group that was led by one of the other participants (staff member) and he had discussed this at length with her and also had a good therapeutic relationship with her. This staff member was also his individual therapist.

Once I had presented the information, he said that he felt that HRBA seemed to be important to him and the information I presented to him was relevant. It seemed like something he hadn't thought a lot about before but really connected with the information. He said it was like a "light going off inside my head".

He felt that one of his main difficulties was not having control over his own life and he felt that other people made decisions for him. This was related to his own self-worth and feeling that if others did not care, then why should he. He felt that if others did not understand his disorder, then many of his rights "go out the window". If he can't stick up for himself then others are invited to take advantage.

NB - I have noted during this interview that I am pulled into comparing this participant's reflections with the staff member who he talks about as being his therapist. I am mindful not to try to bring the two interviews together to "fit the pieces together". I felt as though I needed to treat these interviews as separate from each other so as not to cloud my judgement and compare them in the same way as I would with other interviews.

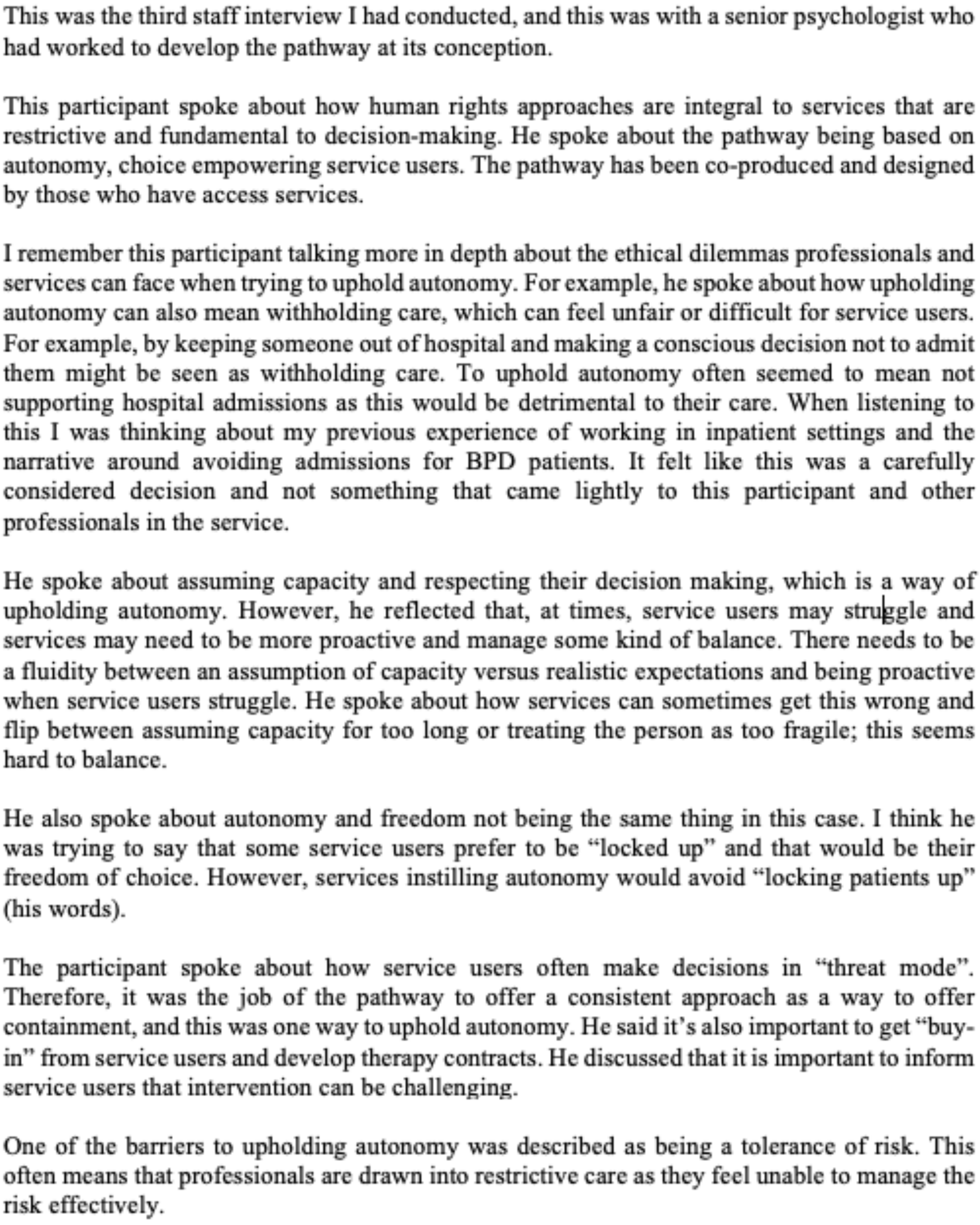
He spoke about how therapy had been incredibly helpful for him. He had a strong therapeutic relationship with his therapist. He initially felt nervous at the start of therapy and did not know what to expect. As time progressed, therapy began to be led by him and felt highly collaborative. He felt that his therapist had empowered him to take back control of his life and this was reflected in him leading therapy. Therapy appears to scaffold him. He said that he has not yet been able to apply his skills in therapy into the "outside world". He thinks he looks more capable in therapy than he actually is.

An important issue that he raised in the interview is how the impact of a community mental health team, as a whole. He didn't just feel that autonomy was impacted by the therapeutic interventions he received. He provided an example of how the team had not informed him of appointments being cancelled and he felt they had spoken to him in a dismissive manner. He feels stupid asking for help and then feels dismissed (feeling stupid as a result) – like a "self-fulfilling prophecy" as he worded it. This impacted his confidence and self-worth and reported to have self-harmed after an interaction with a member of staff. The likelihood of him contacting the admin team again in the future was low and he often contacts his therapist directly to ensure he gets the correct information and feels heard and validated. He reflected that he had split the admin and therapy team when actually the service should be considered as a whole. The admin team don't realise the impact they have the service as a whole is a big part of someone's care. This brings to mind trauma informed care. Teams should be aware of the difficulties service users may have in relation to feeling rejected, abandoned and traumatic interpersonal relationships. Services can cause iatrogenic harm by triggering and feeding into these patterns.

There was some confusion in relation to his diagnosis. It appears that he had received an informal diagnosis of EUPD by a psychiatrist. However, when entering the PD pathway, they completed their own assessment (as this seems to be part of the robust criteria). However, for this participant, this experience added to the confusion of his diagnosis and what help he thought he needed. Receiving the diagnosis was an uncertain time and he described feeling "all at sea"; he didn't know what was 'wrong' with him. I feel this reflects his understanding of mental health difficulties as fitting with a medical model i.e., he is still the same person to know "what's wrong with him" and a diagnostic label shouldn't necessarily change that.

Having other means to keep contact with the service would be helpful, in his opinion. For example, having a text service to remind you of appointments.

Appendix 12: Narrative summary of interview (staff member)



This was the third staff interview I had conducted, and this was with a senior psychologist who had worked to develop the pathway at its conception.

This participant spoke about how human rights approaches are integral to services that are restrictive and fundamental to decision-making. He spoke about the pathway being based on autonomy, choice empowering service users. The pathway has been co-produced and designed by those who have access services.

I remember this participant talking more in depth about the ethical dilemmas professionals and services can face when trying to uphold autonomy. For example, he spoke about how upholding autonomy can also mean withholding care, which can feel unfair or difficult for service users. For example, by keeping someone out of hospital and making a conscious decision not to admit them might be seen as withholding care. To uphold autonomy often seemed to mean not supporting hospital admissions as this would be detrimental to their care. When listening to this I was thinking about my previous experience of working in inpatient settings and the narrative around avoiding admissions for BPD patients. It felt like this was a carefully considered decision and not something that came lightly to this participant and other professionals in the service.

He spoke about assuming capacity and respecting their decision making, which is a way of upholding autonomy. However, he reflected that, at times, service users may struggle and services may need to be more proactive and manage some kind of balance. There needs to be a fluidity between an assumption of capacity versus realistic expectations and being proactive when service users struggle. He spoke about how services can sometimes get this wrong and flip between assuming capacity for too long or treating the person as too fragile; this seems hard to balance.

He also spoke about autonomy and freedom not being the same thing in this case. I think he was trying to say that some service users prefer to be "locked up" and that would be their freedom of choice. However, services instilling autonomy would avoid "locking patients up" (his words).

The participant spoke about how service users often make decisions in "threat mode". Therefore, it was the job of the pathway to offer a consistent approach as a way to offer containment, and this was one way to uphold autonomy. He said it's also important to get "buy-in" from service users and develop therapy contracts. He discussed that it is important to inform service users that intervention can be challenging.

One of the barriers to upholding autonomy was described as being a tolerance of risk. This often means that professionals are drawn into restrictive care as they feel unable to manage the risk effectively.

Appendix 13: Memos (illustrating theme development)

Memo: Interventions => Relational Skill Building

Interview 1: Service User – 09/10/2020

From this first interview it is apparent that therapeutic interventions are a key aspect of treatment and important to understand in the recovery journey. In this interview, the service user seemed dissatisfied with the treatment provision and talked about there being no suitable interventions. They also appeared to have limited awareness of what treatments might/should have been offered to them. They spoke more about informal support being helpful and being able to keep in regular contact with professionals and the importance of having a trusting relationship with them. This was key to “staying well”.

Key points: therapeutic relationship, informal support.

Interview 2: Service User – 18/10/2020

In this interview I tentatively explore their experiences of interventions offered. Conversely to the first interview, this service user spoke of having a wide range of interventions (they named three: MBT, DBT and SCM). They spoke of being able to choose from interventions, this choice being informed and having support from their therapist to consider the best treatment for their needs.

This participant was able to change treatments when they felt it was not suited to their needs. In this interview, the support from the therapist came across and the relationship they had with them was recurring theme in the interview. There were indications about making a choice about treatment and being able to make unwise decisions and also being able to have a say in when a decision is ‘taken away’ from them e.g. inpatient treatment.

Key points: therapeutic relationship, having choice of treatments, informed choice.

Interview 3: Mental Health Professional – 28/10/2020

This was the first interview with a staff member and this helped to better understand a service structure and what treatment standards are. They spoke of three key interventions (MBT, DBT and SCM) again. However, they mentioned about treatment options not being overly structured and there being a “meeting in the middle” of what the service user might want and what the service was reasonable able to offer.

She spoke of working ‘alongside’ service users as being a key part of treatment and this being fundamental to autonomy development. She gave an analogy of practitioners resisting being the ‘lifeguard’ that jumps in to save their client, and instead teaching them to swim. However, she recognised that risk and emotional responses increased the urge to rescue.

She spoke about skills being fundamental to autonomy and someone being taught the skills to cope with their own emotions, again, rather than staff jumping into rescue. This was considered to impede autonomy and be detrimental to their own skill development and being able to cope more independently moving forwards.

Key points: teaching to swim, skills increasing autonomy.

<u>Interview 4: Service User – 18/11/2020</u>

Had little experience of interventions and spoke about being on the waitlist for treatment. She spoke about previously being informed that she would receive DBT and felt that she had been left out of the decision-making process around this. She also spoke about wanting more informal support and wishing that the team knew her better.

Key points: therapeutic relationship, informal support, person-centred, lacking support for treatments.

<u>Interview 5: Mental Health Professional – 11/12/2020</u>

Spoke passionately about having positive relationships with clients and focusing on building skills so they could have positive futures and be independent, not reliant on services. A focus of her client work was to also ensure collaborative decision making and supporting clients to decide on their preferred choice of treatment. She was a practitioner qualified to deliver the treatments offered to service users. She spoke about how treatment modalities were specific to need, but the therapeutic relationship being key to supporting autonomy and not 'leaving' a client to 'flounder', for example.

Key points: collaborative decision making, choice of treatment, therapeutic relationship.

<u>Interview 6: Mental Health Professional – 15/12/2020</u>

Described how autonomy was 'fluid' and dependent upon the context and relational dynamics. For example, autonomy might also mean withholding care, or it might also mean restricting someone's liberties.

Spoke of developing a structured service that is 'containing' for all. Treatments are based on NICE guidance and person-centred to suit needs.

Key points: relational aspect to treatment (and autonomy?), NICE guidance, structured service and interventions.

<u>Interview 7: Mental Health Professional – 19/02/2021</u>

Reflected much more on the relational aspect to treatment and how this can instil autonomy. She spoke about how services are culturally focused on people having choice and control. There appears to be a mismatch between this and clients who perhaps don't want choice and control (because they have never had it?) and because of their low self-worth. She was passionate about increasing autonomy through the therapeutic relationship, working 'alongside' and developing skills for future independence.

Key points: relationships, relational aspect to treatment and skills.

<u>Interview 8: Service User – 19/02/2021</u>

Another service user interview, which feels helpful to balance out the views and opinions of staff members. So far, staff have focused on skills development, wanting to work alongside and looking for ways to increase independence so that service users are not overly reliant on services.

It felt as though this was confirmed in this interview with this service user. He described how he had a good relationship with his therapist and, with her support, he could do more and be more of the person he wanted to be. While he was being supported and scaffolded to increase his life skills (to not be reliant on services) there was a definite sense that he did not feel alone in his journey.

Key points: something (skills, recovery journey?) is being 'shared'.

Interview 9: Mental Health Professional – 19/03/2021

New to the service, she commented on how her knowledge about BPD was historically poor and that she had held (what she considered) to be unhelpful views e.g. about 'responsibility' and assumption of capacity. Now working in a specialist service, she expressed passion about collaboration, co-production and joint decision-making.

Key points: collaboration, developing knowledge.

Interview 10: Mental Health Professional – 19/03/2021

Referenced the lifeguard analogy and expressed his own passion about working alongside clients. There was more of a sense from him about capacity being assumed and this being synonymous with autonomy. This felt like a mismatch and relevant to other aspects of the analysis and developing model. Again, there was a relational component to skills and treatment.

Key points: 'lifeguard', working alongside, assumption of capacity.

Interview 11: Mental Health Professional – 24/03/2021

Strong focus on relational dynamic that plays out between the client and services e.g. the need and risk the client presents with influences service response and their response to need and risk influences the client. Strong focus on good therapeutic relationships and the treatment modality being less important. Spoke about scaffolding clients to be more independent and reflected on her own experiences of autonomy and when she has felt more 'able', independent, empowered etc.

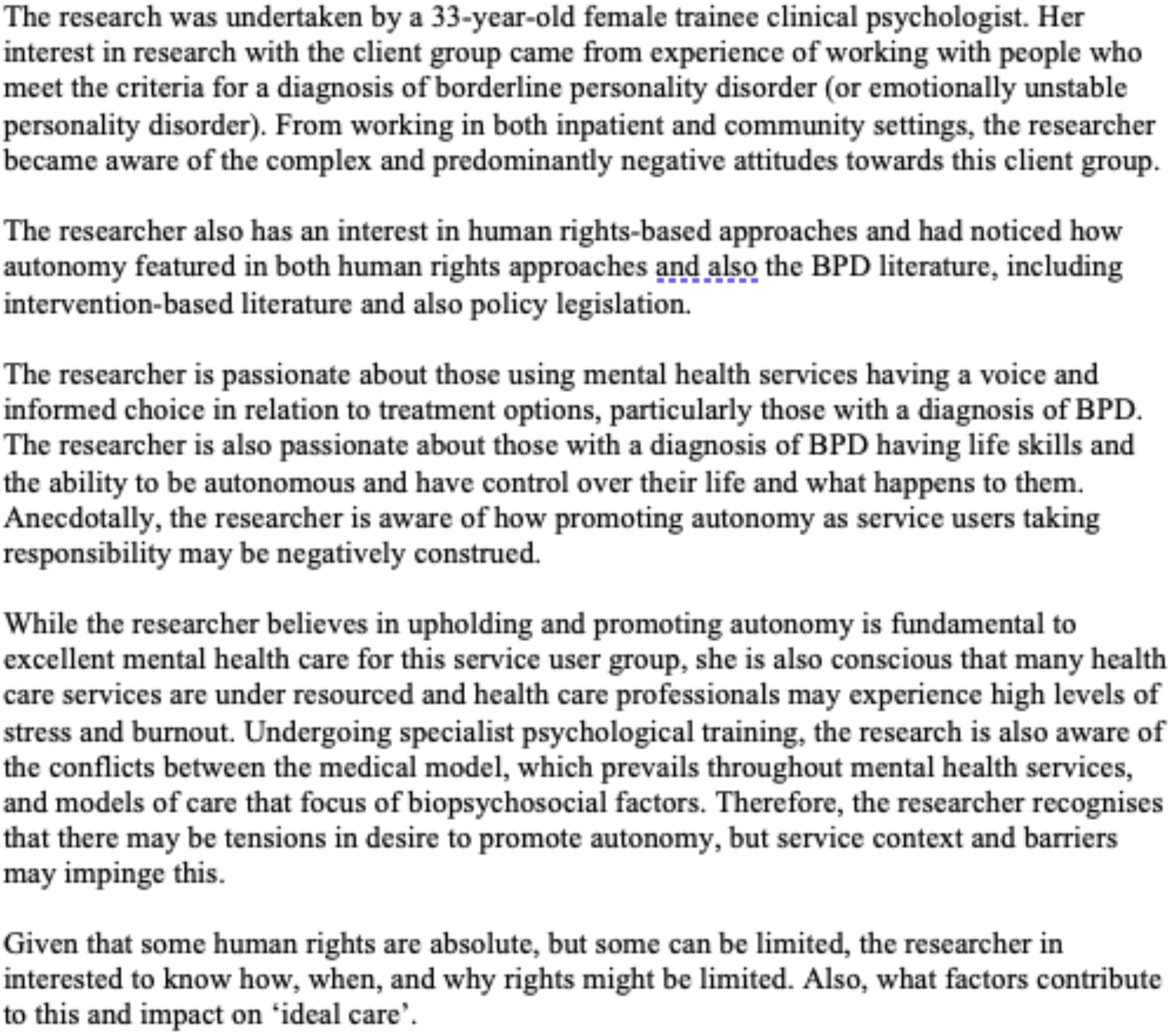
Key points: relationships between service user and services, relational dynamics.

Interview 12: Service User – 09/04/2021

This was the final interview and the service user described being left out of decisions about her care and feeling 'stuck' in the system. This was more related to the general MDT as she felt she had a good relationship with her therapist and spoke about being supported to see her unhelpful patterns and how this played out in her accessing services. For example, she described how her therapist had supported her to discover that she is overly reliant on others and this can be unhelpful in how she accesses and relies on service provision, rather than focusing on her own skill building. Although she felt alone in her support from the MDT, she felt held in mind by her therapist.

Key points: scaffolding, support from therapist and therapeutic relationship.

Appendix 14: Reflexive Statement



The research was undertaken by a 33-year-old female trainee clinical psychologist. Her interest in research with the client group came from experience of working with people who meet the criteria for a diagnosis of borderline personality disorder (or emotionally unstable personality disorder). From working in both inpatient and community settings, the researcher became aware of the complex and predominantly negative attitudes towards this client group.

The researcher also has an interest in human rights-based approaches and had noticed how autonomy featured in both human rights approaches and also the BPD literature, including intervention-based literature and also policy legislation.

The researcher is passionate about those using mental health services having a voice and informed choice in relation to treatment options, particularly those with a diagnosis of BPD. The researcher is also passionate about those with a diagnosis of BPD having life skills and the ability to be autonomous and have control over their life and what happens to them. Anecdotally, the researcher is aware of how promoting autonomy as service users taking responsibility may be negatively construed.

While the researcher believes in upholding and promoting autonomy is fundamental to excellent mental health care for this service user group, she is also conscious that many health care services are under resourced and health care professionals may experience high levels of stress and burnout. Undergoing specialist psychological training, the research is also aware of the conflicts between the medical model, which prevails throughout mental health services, and models of care that focus of biopsychosocial factors. Therefore, the researcher recognises that there may be tensions in desire to promote autonomy, but service context and barriers may impinge this.

Given that some human rights are absolute, but some can be limited, the researcher in interested to know how, when, and why rights might be limited. Also, what factors contribute to this and impact on ‘ideal care’.

Appendix 15: Participant Feedback Letter

DClin Psychology Programme
School of Psychology
Whelan Building, Quadrangle
Brownlow Hill
LIVERPOOL
L69 3GB
Tel: 0151 794 5530/5534/5877
0151 795 5446
www.liverpool.ac.uk/psychology/study/doctorate

August 2021

Dear participant,

Research Findings: Understanding autonomy in a specialist community-based service for Borderline Personality Disorder.

Thank you for volunteering to take part in the research project exploring autonomy in those with a diagnosis of borderline personality disorder (BPD). I wanted to write to you to summarise the key findings as a personal record to you all and to demonstrate your invaluable contributions.

The research included five service users and seven mental health professionals. Each participant offered a unique contribution to the study, and I am extremely grateful to everyone for allowing me to hear about your passion and willingness to reflect on your personal experiences of utilising, or working in, specialist mental health services. By offering your time to take part in an interview and talk about your experiences this has enabled the discovery of some important and instrumental findings.

The purpose of the research was to investigate autonomy in those with a diagnosis of BPD and how this relates to utilisation of relevant mental health services. The study adopted a Human

Rights-Based Approach (HRBA) using the FREDA principles. Autonomy can be understood as an individual's self-determination and the ability to make free choices. National legislation (NICE, 2009) emphasises the importance of mental health services promoting autonomy and choice for individuals with a diagnosis of BPD specifically.

Contained within the subsequent paragraphs is a summary of findings from the research project. Findings are discussed as main themes and subthemes which were developed from detailed analysis of qualitative data obtained from all interviews undertaken.

1. **Relational autonomy (main theme)**: Autonomy was not considered to occur within a vacuum or be dependent upon a single individual. Instead, autonomy was thought of as dynamic and dependent of several different factors:

Subthemes:

- <u>Relational skill building:</u> It was important for service users to have a range of therapies to choose from that was suited to their needs. Mental health professionals spoke about the importance of supporting service users to be more self-sufficient and learn new coping skills. There was analogy of mental health professionals 'teaching to swim', rather than a lifeguard that dives into save the service users they work with.
- <u>Choice and involvement:</u> Service users should have a choice in treatment options and be involved in decisions about their care. Mental health professionals were passionate about service user rights in making their own decisions, irrespective of others' views.
- <u>Empathic staff and services:</u> Service users experience of treatment should be empathic and validating. Positive experiences in accessing treatment were associated with feeling heard and understood.
- <u>Flexible and responsive services</u>: A service approach that was structured, yet flexible, and containing was deemed important for both staff and service users. Service users experience distress was understood to be due to several stressful aspects of their lives including their experience of trauma and adversity. Mental health professionals spoke about how a structured service model also made them feel safe and provided them with a clear rationale for decision-making processes in relation to treatment and risk.
- <u>Human rights and policy:</u> Some service user participants had not heard of this approach, but all participants considered HRBA's to be integral to working with individuals with

a diagnosis of BPD. Mental health professionals identified many similarities between rights-based approaches and their own professional standards.

2. **Challenges to upholding autonomy (main theme):** Due to the dynamic nature of autonomy, there were times were services users' autonomy inevitably felt impacted and this was considered to be dependent on a range of factors:

Subthemes:

- <u>Understanding and implementing rights:</u> There was recognition that not all service users and mental health professionals would have knowledge of how rights-based approaches could be applied to healthcare. Lack of knowledge may have negative impacts for care.
- <u>Beliefs and attitudes:</u> All participants acknowledged the prevalence of negative attitudes related to the BPD diagnosis. Unfortunately, there were experiences where lack of understanding, negative attitudes and stigma impacted care.
- <u>Risk:</u> Many of you spoke about risk and the difficulties individuals with BPD experience in relation to self-harm and suicidal ideation. Mental health professionals many find it stressful working in systems where they may feel unsupported in carrying high complex caseloads. This may lead to restrictive care and service users spoke about being poorly supported when they were in crisis.
- <u>Decision-making:</u> While it was important for individuals with BPD to be supported to make their own decisions, there were times when they needed additional support or where they preferred for choice to be taken away and for a decision to be made for them. Sometimes it was challenging to find the right balance.
- <u>Nature of BPD:</u> Many individuals with a diagnosis of BPD might have had experiences of trauma where their autonomy has been taken away. Both service users and mental health professionals spoke about how services may be retraumatising and difficulties may 'resurface'. Autonomy was considered to fluctuate, and it was important that professionals and services respond and adapt appropriately.
- <u>Relationships with professionals and services:</u> Poor relationships between service users and professionals impacted experiences of care and treatment. Power imbalances may have negative consequences, such as re-traumatisation and service users not feeling heard or supported.

- Resources and service performance: Lack of resources and long wait lists negatively impacted service user autonomy. Overly rigid local service models and national guidance may limit the treatments available to service users.

3. **Edges of autonomy (main theme):** Where the above factors (challenges to autonomy) came into play, and relational autonomy was difficult to maintain, service users were thought to be more likely to fall into one of two categories:

Subthemes:

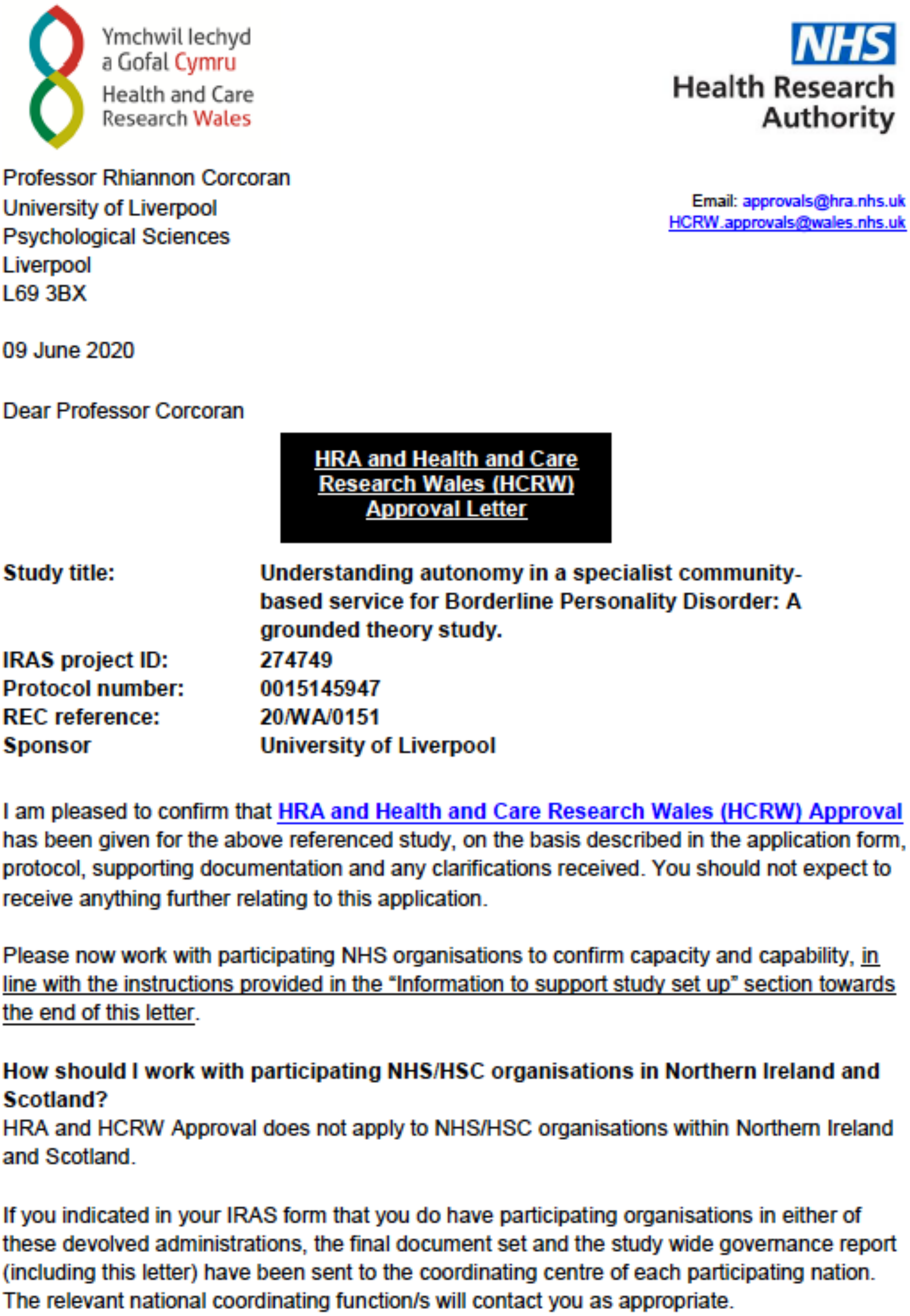
- Forced autonomy: This is where service users feel abandoned and unsupported by services and professionals. Mental health professionals might make assumptions about service user's capacity and ability to make decisions and be self-sufficient.
- Diminished autonomy: Alternatively, where services 'dive in' too soon and take decisions away from service users their autonomy might be diminished. There were times were service users preferred this as they felt held in mind by services and felt they were in receipt of 'perfect care'. However, there were thoughts around the risk of service users becoming 'overly reliant' on services at times.

Hopefully this research goes some way to enhance mental health services for individuals with a diagnosis of BPD. I would like to thank you again for your contribution to the research.

Best wishes

Rebecca Goodfellow
Trainee Clinical Psychologist

Appendix 16: NHS Ethical Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
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Professor Rhiannon Corcoran
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Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

09 June 2020

Dear Professor Corcoran

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Understanding autonomy in a specialist community-based service for Borderline Personality Disorder: A grounded theory study.**
IRAS project ID:	**274749**
Protocol number:	**0015145947**
REC reference:	**20/WA/0151**
Sponsor	**University of Liverpool**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

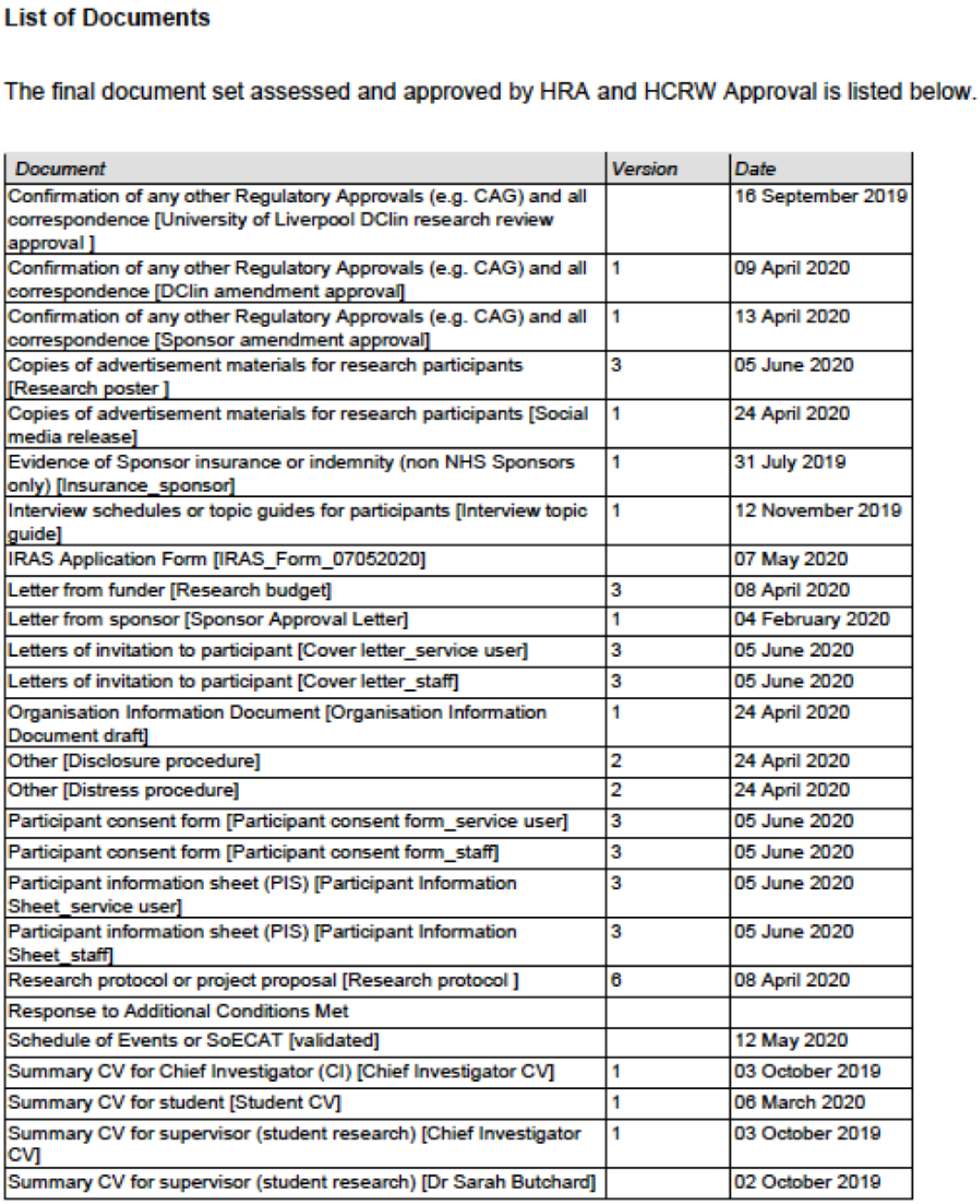
Your IRAS project ID is **274749**. Please quote this on all correspondence.

Yours sincerely,
Penny Beresford

Approvals Specialist

Email: HCRW.approvals@wales.nhs.uk

Copy to: *Mr Alex Astor*



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [University of Liverpool DClin research review approval]		16 September 2019
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [DClin amendment approval]	1	09 April 2020
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Sponsor amendment approval]	1	13 April 2020
Copies of advertisement materials for research participants [Research poster]	3	05 June 2020
Copies of advertisement materials for research participants [Social media release]	1	24 April 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance_sponsor]	1	31 July 2019
Interview schedules or topic guides for participants [Interview topic guide]	1	12 November 2019
IRAS Application Form [IRAS_Form_07052020]		07 May 2020
Letter from funder [Research budget]	3	08 April 2020
Letter from sponsor [Sponsor Approval Letter]	1	04 February 2020
Letters of invitation to participant [Cover letter_service user]	3	05 June 2020
Letters of invitation to participant [Cover letter_staff]	3	05 June 2020
Organisation Information Document [Organisation Information Document draft]	1	24 April 2020
Other [Disclosure procedure]	2	24 April 2020
Other [Distress procedure]	2	24 April 2020
Participant consent form [Participant consent form_service user]	3	05 June 2020
Participant consent form [Participant consent form_staff]	3	05 June 2020
Participant information sheet (PIS) [Participant Information Sheet_service user]	3	05 June 2020
Participant information sheet (PIS) [Participant Information Sheet_staff]	3	05 June 2020
Research protocol or project proposal [Research protocol]	6	08 April 2020
Response to Additional Conditions Met		
Schedule of Events or SoECAT [validated]		12 May 2020
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	03 October 2019
Summary CV for student [Student CV]	1	06 March 2020
Summary CV for supervisor (student research) [Chief Investigator CV]	1	03 October 2019
Summary CV for supervisor (student research) [Dr Sarah Butchard]		02 October 2019

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

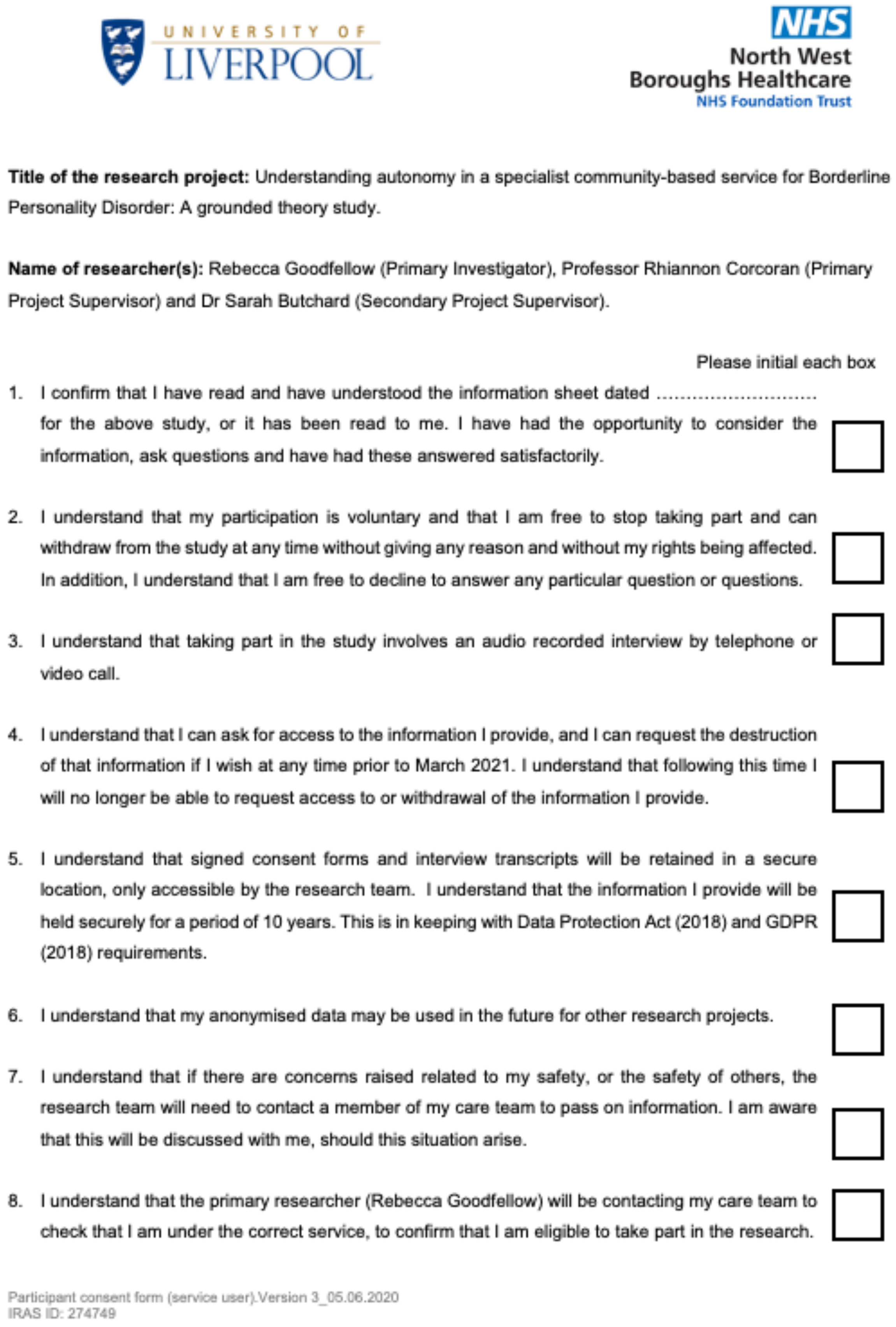
Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is one site type where all activities according to the protocol will be undertaken.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No application for external funding will be made.	A principal investigator is expected at site.	Use of identifiable patient records held by an NHS organisation to identify potential participants without their prior consent should be undertaken by a member of the direct care team for the patient, so it would not normally be acceptable for this to be done by staff not employed by that organisation. The activities at the participating NHS organisation will be undertaken by local staff therefore it is expected that adequate contractual relationship with the host organisation are already in place. Where contractual arrangements are not already in

					place, network/external staff (or similar) undertaking research activities would be expected to obtain Honorary Research Contracts on the basis of a Research Passport (if university employed) or a Letter of Access on the basis of an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). Enhanced DBS checks (incl. appropriate barred list checks) and occupational health clearance would be appropriate.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 17: Participant consent form (service user)



UNIVERSITY OF LIVERPOOL

NHS
North West
Boroughs Healthcare
NHS Foundation Trust

Title of the research project: Understanding autonomy in a specialist community-based service for Borderline Personality Disorder: A grounded theory study.

Name of researcher(s): Rebecca Goodfellow (Primary Investigator), Professor Rhiannon Corcoran (Primary Project Supervisor) and Dr Sarah Butchard (Secondary Project Supervisor).

Please initial each box

1. I confirm that I have read and have understood the information sheet dated .... for the above study, or it has been read to me. 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 stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
3. I understand that taking part in the study involves an audio recorded interview by telephone or video call. ☐
4. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to March 2021. I understand that following this time I will no longer be able to request access to or withdrawal of the information I provide. ☐
5. I understand that signed consent forms and interview transcripts will be retained in a secure location, only accessible by the research team. I understand that the information I provide will be held securely for a period of 10 years. This is in keeping with Data Protection Act (2018) and GDPR (2018) requirements. ☐
6. I understand that my anonymised data may be used in the future for other research projects. ☐
7. I understand that if there are concerns raised related to my safety, or the safety of others, the research team will need to contact a member of my care team to pass on information. I am aware that this will be discussed with me, should this situation arise. ☐
8. I understand that the primary researcher (Rebecca Goodfellow) will be contacting my care team to check that I am under the correct service, to confirm that I am eligible to take part in the research. ☐

Participant consent form (service user).Version 3_05.06.2020
IRAS ID: 274749

9. I agree to be contacted to discuss the results of the study. I will be invited to attend a focus group or have an individual conversation, depending on social distancing measures in place at the time. ☐

10. I agree to take part in the above study. ☐

___________________________	__________	_______________________
Participant name	Date	Signature
___________________________	__________	_______________________
Name of person taking consent	Date	Signature

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Appendix 18: Participant consent form (staff)

Title of the research project: Understanding autonomy in a specialist community-based service for Borderline Personality Disorder: A grounded theory study.

Name of researcher(s): Rebecca Goodfellow (Primary Investigator), Professor Rhiannon Corcoran (Primary Project Supervisor) and Dr Sarah Butchard (Secondary Project Supervisor).

Please initial each box

1. I confirm that I have read and have understood the information sheet dated ……………………… for the above study, or it has been read to me. 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 stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐

3. I understand that taking part in the study involves an audio recorded interview by telephone or video call. ☐

4. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to March 2021. I understand that following this time I will no longer be able to request access to or withdrawal of the information I provide. ☐

5. I understand that signed consent forms and interview transcripts will be retained in a secure location, only accessible by the research team. I understand that the information I provide will be held securely for a period of 10 years. This is in keeping with Data Protection Act (2018) and GDPR (2018) requirements. ☐

6. I understand that my anonymised data may be used in the future for other research projects. ☐

7. I understand that if there are concerns raised related to my safety, or the safety of others, the research team will need to contact a member of my care team to pass on information. I am aware that this will be discussed with me, should this situation arise. ☐

8. I understand that the primary researcher (Rebecca Goodfellow) will be contacting my care team to check that I am under the correct service, to confirm that I am eligible to take part in the research. ☐

9. I agree to be contacted to discuss the results of the study. I will be invited to attend a focus group or have an individual conversation, depending on social distancing measures in place at the time. ☐

10. I agree to take part in the above study. ☐

______________________	________	___________________
Participant name	Date	Signature
______________________	________	___________________
Name of person taking consent	Date	Signature

Research Team Contact Details

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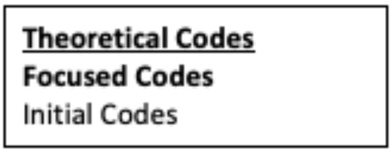
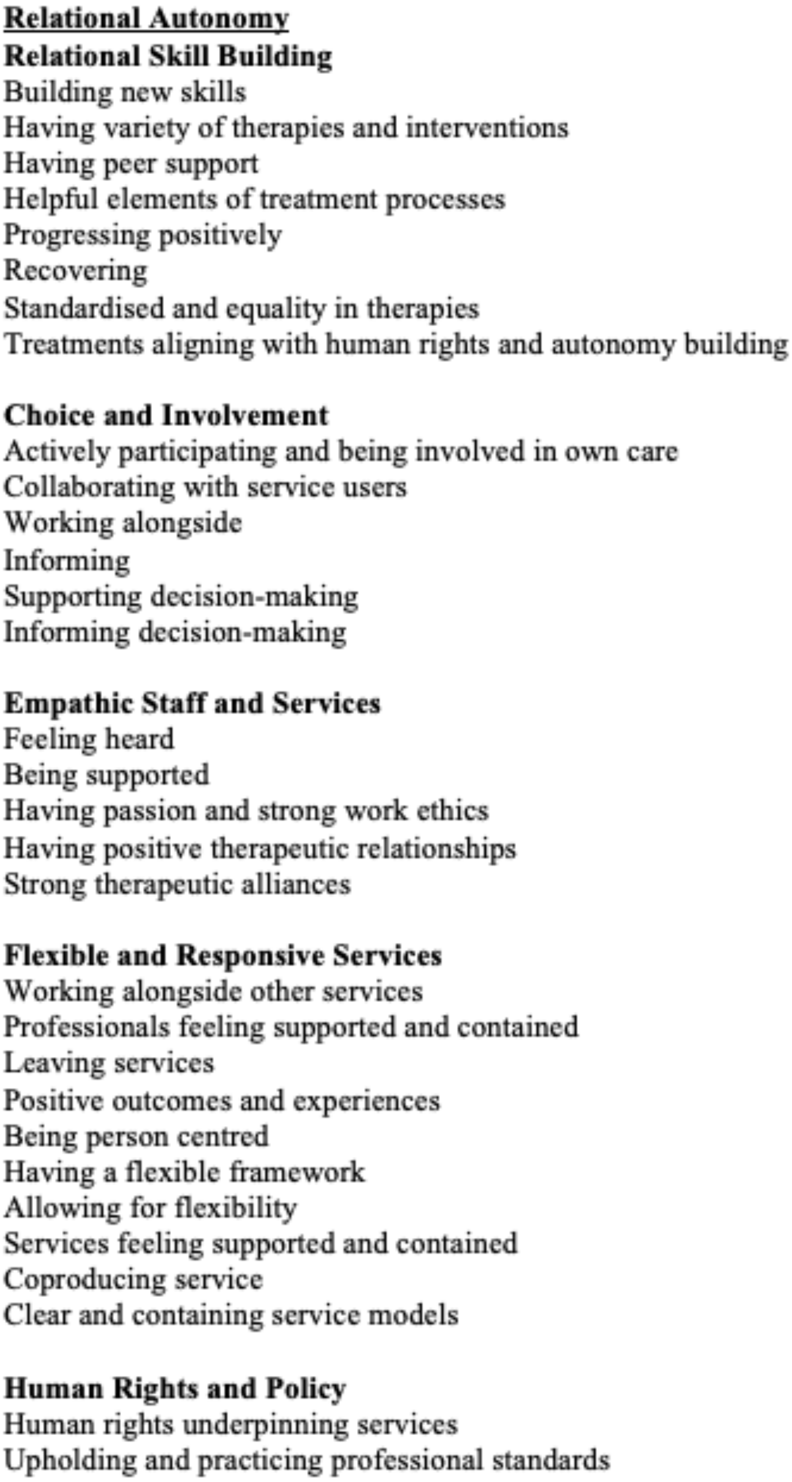
Appendix 19: Mapping Focused Codes onto Theoretical Codes



Theoretical Codes
Focused Codes
Initial Codes



Relational Autonomy
Relational Skill Building
Building new skills
Having variety of therapies and interventions
Having peer support
Helpful elements of treatment processes
Progressing positively
Recovering
Standardised and equality in therapies
Treatments aligning with human rights and autonomy building

Choice and Involvement
Actively participating and being involved in own care
Collaborating with service users
Working alongside
Informing
Supporting decision-making
Informing decision-making

Empathic Staff and Services
Feeling heard
Being supported
Having passion and strong work ethics
Having positive therapeutic relationships
Strong therapeutic alliances

Flexible and Responsive Services
Working alongside other services
Professionals feeling supported and contained
Leaving services
Positive outcomes and experiences
Being person centred
Having a flexible framework
Allowing for flexibility
Services feeling supported and contained
Coproducing service
Clear and containing service models

Human Rights and Policy
Human rights underpinning services
Upholding and practicing professional standards

Having explicit guidance and policy
Policies and legislation aligning with human rights
Human rights fitting within pathways and services
Having knowledge and awareness of human rights

Challenges to Upholding Autonomy
Understanding and implementing rights
Intentionally withholding care
Conflicting ideas relating to autonomy
Difficulties and failures in upholding rights
Lacking awareness and knowledge of human rights

Beliefs, Attitudes and Labelling
Medical model frameworks
Medicalised models of mental health
Holding negative attitudes
Attitudes that challenge the medical model
Held beliefs
Linking capacity, autonomy, and responsibility
Lacking understanding

Risk
Utilising clinical judgement
Being fearful
Increasing risk
Increasing restrictive practices
Reactive and emotional responses
Symptomology and risk

Decision-making
Seeking restrictive care
Conflicts in decision-making
Detriments of restrictive care
Being admitted to hospital
Lacking capacity and decision-making
Restrictions in hospital
Taking away decisions
Having the right to make own decisions

Nature of BPD
Individual experience of autonomy and human rights
Development of difficulties
Adjusting and adapting
Fluctuating autonomy
Current and continuing difficulties

Relationships with professionals and services
Responding to service users
Relational patterns
Having poor relationships with services/professionals

BPD symptomology ‘interaction’ and relational patterns
Lacking skills
Challenges to interpersonal style
Professionals knowing best
Power imbalances

Service performance and resource
Doing the best we can and adapting
Impact of staff quota
Extensive waiting times
Lack of funding
Detriments of resources on autonomy/human rights
Old ways of working
Poor parts to services
Imposed limitations by guidance
Harmful services
Interventions unhelpful
Lacking sufficient information
Requiring improvements
Fixed and inflexible services
Lack of clarity about service pathway
Lacking consistency and continuity
Perpetuating systemic issues
Integrating services

Edges of Autonomy
Forced Autonomy
Assuming knowing and understanding
Getting worse
Increasing risk
Backing off from services
Assuming capacity
Feeling abandoned
Lack of support
Dismissing and invalidating
Not being listened to
Needs not being met

Diminished Autonomy
Dangers of becoming over-reliant
Disempowering
Diminishing autonomy
Lack of involvement in decision-making

Appendix 20: Additional Quotes

Theoretical Code	Focused Code	Additional Quote
Relational Autonomy	Relational Skill Building	*"We've got three therapy options on the Pathway and we've got coping skills, as well. Then we've got the potential for, some kind of, bespoke therapy. I think those therapies being there in place… I think that's definitely a positive thing"* (Alex, mental health professional). *"There's a couple of people really similar to me in the group. it's one of the first things that actually made me feel a bit better about me self, actually like, I wasn't on me own with it"* (Paul, service user).
	Choice and Involvement	*"Rather than telling somebody what to do, you're more likely to hit a brick wall, rather if you're working alongside a client and give them a choice and, you're more likely to get potentially a better outcome"* (Alan, mental health professional). *"There's a process by me having free will and choice, which is what we're saying autonomy is"* (Brian, service user). *"Yeah, I think I, I feel more, Autonomous with them. Because, you know, they understand that I have choices and stuff and that"* (Kelly, service user).
	Empathic Staff and Services	*"I feel really passionate about erm, this line of work and I think even more passionate in the last 12 months and, I've been taught, in certain ways and beautifully, by a few other people…I'm really keen, to kind of you know, make services more, approachable, erm, and appropriate and, helpful and supportive for people with, with personality disorder" (*Alex, mental health professional). *"When you are listened to and you get the opportunity to do so, and you see the actions of that, you're not as bad as you thought you are. Then that gives you the evidence to challenge your thoughts, because what you said was actually listened to"* (Brian, service user). *"I feel like they're really there if that makes sense? They're really understanding and really empathic"* (Chloe, service user).

	Flexible and Responsive Services	*“I think the pathway has been, what it is good is because it's been developed in conjunction with Experts by Experience. So, they've been through it so it's, it's co-produced and it's not been prescribed so it's it is, took service users in mind”* (Alan, mental health professional). *“We even get clients who don't want to do multimodal treatments because they point blank don't want to do groups. Which again limits the Pathway, because it, it's all multimodal. But we will look at whether individual psychology off the Pathway”* (Louise, mental health professional).
	Human Rights and Policy	*“Human Rights, for me, is the idea that everybody's born equal, and we have to adhere to everyone's right around equality… Work along that principle that everybody is born equal and that everybody deserves equal voice, equal understanding, equal delivery of optimum care… In health care I think that it's the probably it’s the highest context marker”* (Anne, mental health professional).
Challenges to Upholding Autonomy	Understanding and Implementing Rights	*“In the day to day, I think it's something that becomes quite implicit and, I can see that that can be risky when it becomes something assumed. Which I think it probably does”* (Emma, mental health professional). *“If you went into hospital and they read out these sort of rights to you and stuff, but, I was just really surprised that that was kind of never done. Do you know what I mean? Some people, in hospital might not know what their rights are and stuff”* (Kelly, service user).
	Beliefs, Attitudes and Labelling	*“Often, I think of clients with BPD as almost a very repressed group in terms of a voice, you know. Up until what, when was it, 1990 something, erm, no longer a diagnosis of exclusion, if we were thinking about policy documentation”* (Anne, mental health professional). *“I don't like it, like it's called the Personality Disorder service. I don't like that from the get-go. Cos it feels like, your personality, like you as a person, aren't right. I don't like that”* (Sophie, service user).
	Risk	“Whenever, if I'm in a crisis mode, then they'll say everything and anything to kind of get you to calm down” (Sophie, service user). *“Sometimes risk can trigger different emotional responses in staff members and that might mean that people quite quickly jump on board and make decisions, on the behalf of service users. And sometimes, that might need to*

		happen, to keep people safe, I respect that. But, I think, sometimes there can be a, a breakdown, in the interplay between different services around that" (Emma, mental health professional).
	Decision-making	*"I feel like especially like, when it's getting towards, crisis point, erm, I feel that's when I don't have any say in my care, but that's when, I know that things are starting to be taken out of my hands, which I feel is beneficial, erm, purely for the fact that when I'm getting to crisis point"* (Chloe, service user). *"There's probably times where, if that's, gone too much to a crisis point, or something, quite significant or quite severe has happened, then I think mental health services generally do have to, then kind of take, responsibility or, make some decisions and take some control"* (Alex, mental health professional).
	Nature of BPD	*"So, then you'll have a service that says, well choice, control, and actually, someone's saying, actually I don't want choice, I don't want control, I'm not sure if I am worth anything… Maybe autonomy's never been offered, maybe it's never been fostered, maybe relationally no one's every been invited into that position"* (Anne, mental health professional).
	Relationships with professionals and services	*"If you're feeling like that you need to speak to staff, don't send me stuff like that. So, straightaway it's like, I can't build a relationship with someone that's like that"* (Kelly, service user). *"If they didn't interrogate you all the time, that's how it feels like, when they ask you question after a question after question, like if they just lay off a bit, you know"* (Sophie, service user).
	Service Performance and Resource	***"***Oh, it was horrific, absolutely horrific and that's why, even now if I was in severe crisis, I'd get in touch with my therapist, I wouldn't, wouldn't ring crisis line cos there absolutely useless"* (Kelly, service user). *"My CPN was off for like 3 weeks, three and a half weeks, so no one stepped in, but in that time, my mental health like had really gone downhill, and erm, so they didn't really do anything, to be honest"* (Sophie, service user). *"Some people have been waiting a long time for the interventions. Just because there's nobody to do them, so, which that probably does infringe some of their rights to a degree"* (Elizabeth, mental health professional).

		"I think it can be quite difficult to ask somebody to make a decision about a treatment that they might not actually be able to receive for another six months. Erm, so staffing capacity and wait lists, I do think impact on, autonomy" (Emma, mental health professional).
Edges of Autonomy	Forced Autonomy	*"…There's an assumption around autonomy if you have a capacity for that, but what it doesn't understand is the nuances of the person's own felt experience of autonomy"* (Anne, mental health professional). *"I honestly don't know, sometimes I think they just don't think that because we're suicidal so much, that oh it's just, they're just suicidal again"* (Chloe, service user).
	Diminished Autonomy	*"…sometimes you can get quite reliant on others, do you know what I mean like? It's, that's one of the traits that I have where, I do sort of depend on other people"* (Kelly, service user). *"It tends to be that people can become reliant on that one person and if that one person goes off sick or leaves or has a baby or whatever then then that's when, anecdotally anyway, certainly…I don't know if there is, I'm sure there probably is evidence to support this as well…that's when people would have, would go into crisis"* (Elizabeth, mental health professional).