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Exploring the subjective experiences of Depersonalisation Disorder, beliefs and attributions of the disorder and treatment

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VOLUME I:

SYSTEMATIC LITERATURE REVIEW

EMPIRICAL RESEARCH PROJECT

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Chapter 1

Systematic Literature Review:

Cognitive and Affective Profile of Depersonalisation Disorder

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Abstract

Background:

Depersonalisation disorder (DPD) is characterised by chronic and continuous feelings of detachment from one's self. Perceptual changes, emotional numbing, and memory and attentional difficulties are also often reported (Sierra, 2009). DPD continues to be not well understood, under-researched and under-diagnosed (Sierra, 2009). This review aims to improve the understanding of this disorder by consolidating the common patterns of cognitive functioning and emotional processing within the DPD population.

Methods:

A systematic review, based on PRISMA guidelines (Page et al., 2021), was conducted on case-control studies investigating cognitive and affective processes within the DPD population. Studies were selected from Web of Science, PUBMED, PsycInfo, SCOPUS, MEDLINE and EMBASE. NIHR case-control quality rating tool was used to evaluate the quality of studies included.

Findings:

We included 23 papers in this review, with 6 studies investigating the cognitive abilities of DPD, and 17 studies examining emotional processing within DPD patients. People with DPD appear to have normal levels of cognitive abilities, although some differences in memory, attention and visuospatial abilities are consistent with their subjective complaints. Established effects of emotion on cognition such as emotionally-enhanced memory and emotionally-biased reasoning have also largely remained intact in the DPD population, as well as the cognitive aspects of affective processes, like cognitive empathy and emotional recognition despite high levels of alexithymia within the DPD population. Furthermore, DPD's affective response appears to be associated with a neural inhibitory mechanism due to the activation of the prefrontal cortex after the processing of aversion emotions from the insula region, which suppresses the subjective experience of emotion and autonomic markers of emotion. People with DPD also struggle with interoceptive identification and affective experiencing of emotions.

Conclusions:

It is unclear whether the differences in cognitive abilities noted above are indicative of actual neuropsychological deficits, or if they could be better explained by a reduced working memory and attentional capacity, leading to limited perceptual resources allocated for other aspects of experience. Retention of cognitive aspects of empathy, emotional recognition, and processing of emotional stimuli before inhibitory response may explain the preservation of regular modulation of cognitive

functioning by emotion. The limitations of this review include a small number of included studies despite the broad scope, and small sample sizes within many of the included studies. Variable methodology across studies also made quantitative analysis difficult to conduct in this review. More research is needed in this population, particularly around the perceptual capacity of people with DPD and its relationship with excessive symptom monitoring, which is common amongst people with DPD.

Introduction

Despite a long history of clinical recognition and description (Brauer et al., 1970), depersonalisation (DP) and Depersonalisation Disorder (DPD) is still not well understood by researchers and clinicians alike, often being misdiagnosed or under-recognised (Sierra, 2009). DP is often described as the experience of feelings of unreality and detachment from oneself, usually co-occurring with emotional numbing and perceptual disturbances amongst other symptoms. It is also often accompanied by derealisation (DR), in which the sense of detachment and unreality is related to the external environment. Both DP and DR symptoms are relatively common even in the general population, as lifetime prevalence rates are estimated to be between 26-74% (Hunter et al., 2004). DPD, also known as Depersonalisation and Derealisation Disorder (DPDR), is labelled as the chronic and continuous suffering of DP and/or DR symptoms, and prevalence rates of clinically significant levels of DP/DR were found to be between 1-2% (Hunter et al., 2004). People suffering from DP are not considered delusional, as they still retain insight that their experiences are subjective and not objective reality.

The aetiology of DPD remains unclear, although several studies have pointed toward DPD as the result of a maladaptive defensive mechanism to cope with overwhelming and aversive emotions, which may be predisposed by an emotionally traumatic childhood (Ó Laoide et al., 2017; Simeon et al., 2001). There are also some suggestions that the severity of DPD may be mediated by culture, as Sierra-Siegert & David (2007) found that people from individualistic cultures were more likely to experience depersonalisation during panic, as compared to people from more collectivist cultures. A significant minority of DPD patients also attribute the onset of their chronic DP symptoms to illicit drug use, but no distinct differences were found between the clinical presentations of drug-induced and non-drug-induced groups, when matched for age and gender (Medford et al., 2003).

Cognitive Profile of DPD

People with DPD often complain of various cognitive difficulties, including poor memory, attention and perceptual differences. Although many people with DPD may continue to function, they often describe not performing at 'full capacity'. These cognitive difficulties are sometimes referred to as 'brain fog' (Simeon & Abugel, 2006). This may place a heavier cognitive load on DPD patients, and impact on their cognitive capacities according to the Cognitive Load Theory (Sweller et al., 2011). These subjective reports seem supported by research findings of DPD participants presenting with greater difficulty completing tasks when under larger perceptual load (Guralnik et al., 2000). Despite not suffering from amnesia common to other dissociative disorders, in that they do not typically report lost blocks of time, people with DPD usually describe their memories as 'hazy' or like watching a film.

Given the natures of these complaints, Guralnik and her team (2000, 2007) examined the cognitive abilities of people with DPD through the use of standardized neuropsychological testing, and the results suggested there may be slight attentional and perceptual differences between DPD patients and healthy controls. However, despite these differences, most cognitive domains of people with DPD remain intact, and their cognitive profiles appear to be distinct from the general cognitive decline common in other disorders such as schizophrenia or depression. It remains unclear if the central cognitive deficit is attentional difficulties resulting in poor memory, or if memory is the core impairment, or if both are implicated (Simeon & Abugel, 2006).

Affective Profile in DPD

Another core cognitive feature of DPD is emotional numbing, or deaffectualization. People with DPD often report a disconnect between knowing what they should be feeling, and actually experiencing the emotion. Emotional maltreatment in childhood has been found to be a key predictor for the development of depersonalisation disorder (Simeon et al., 2001), and research has found evidence to link childhood trauma and difficulties with emotional processing and regulation (Marusak et al., 2014; McCrory et al., 2013). The identifying and processing of emotion and emotional information, in themselves or others, has also been reported to be more difficult for people with DPD, and alexithymia has been found to be a predictor of DP symptoms (Lemche et al., 2013a).

Given the abnormal processing of emotion in DPD, regular emotional modulation of cognitive functions may also be impacted. Memory and attention have been shown to be influenced and directed by emotions (Brosch et al., 2013): emotionally arousing events are often better remembered than neutral events, a phenomenon referred to as 'emotionally enhanced memory' in the literature, as more perceptual resources are dedicated to emotional stimuli (Dunsmoor et al., 2019). Conversely, peripheral neutral stimuli may be out-competed for perceptual resources, resulting in the related phenomenon 'emotion-induced blindness' (Wang et al., 2012). However, the emotional disconnect experienced by people with DPD appear to disrupt these processes. Salami et al., 2020 provided a systematic review of the neural activity of DPD symptoms, as measured by electroencephalogram (EEG) and highlighted Quaedflieg et al's (2013) EEG study on the relationship between depersonalisation and emotion-induced blindness. It was found that emotional distractors have a lower impact in terms of event-related potential (ERP) on subsequent processing tasks for participants scoring higher on DP measures, suggesting an inverse relationship between depersonalisation and emotion-induced blindness.

More recently, attention has been paid to the neurobiological processes underlying the abnormal emotional processes in DPD, specifically skin-conductance and functional magnetic

resonance imaging (fMRI) studies. Phillips et al (2018) provided a brief overview of the neurobiological research using fMRI undertaken by her specialist research unit focussing on DPD. She summarized that 'emotion centres' in the brain, such as the insula, remain inactivated despite exposure to aversive stimuli. This inhibition may be due to the activation of the prefrontal cortex, the brain region associated with executive functioning. Phillips et al (2018) also briefly outlined that based on skin-conductance studies, DPD patients display a flattened autonomic response to emotional stimuli, despite intact emotional recognition. This was also supported by Horn et al (2020), who also conducted a more in-depth systematic review on the electrodermal activity during emotional response in depersonalisation. Horn et al (2020) found that DPD patients tend to have an abnormally high resting electrodermal activity, suggesting a higher baseline of sympathetic arousal, and that DPD participants are generally in a heightened state of alertness.

Aim of Paper

In this paper, we aim to perform a systematic review and provide a summary of the findings on the cognitive and affective processes in people with DPD. To date, there has also not been a systemic review on the cognitive abilities of people with DPD, despite the prevalence of memory and attentional complaints within the DPD population. A deeper understanding of these cognitive differences may help consolidate the understanding of a cognitive profile, and potentially lead to the development of more effective strategies to help people cope with their subjective cognitive complaints. A comprehensive understanding of the abnormal emotional processing in DPD, its relation to other cognitive functions, and their neurobiological underpinnings could also help to further expand the understanding of the underlying processes within DPD, and potentially aid in the development of more targeted interventions.

Review Methodology

Search strategy

The search was conducted in 6 major electronic databases: Web of Science, PUBMED, PsycInfo, SCOPUS, MEDLINE and EMBASE. The searches in all databases were restricted to the years 1990 to present, except for the PsycInfo database as this function was not provided. As such, papers prior to 1990 from the PsycInfo database were manually removed. The databases were last searched in August 2021.

The search terms used consisted of two main sets. The first set included keywords such as depersonal* disorder, depersonal* and DPD, with the asterisk (*) used as a truncation symbol to account for the British and American spelling for depersonalisation. The second set of keywords include cognit* OR executive funct* OR emotion* OR affect* OR deaffect*. The keywords within each set were separated using the Boolean operator OR, and both sets were linked together using the Boolean operator AND.

Preliminary searches produced numerous studies investigating burnout in various professions due to the identification of non-clinical depersonalisation as a symptom of burnout. As such, to more efficiently search for papers investigating chronic clinical depersonalisation as per the diagnosis of DPD, 'burnout' was also specified to be ignored in the searches using the Boolean operator NOT.

Paper Selection and Screening Process

Only observational studies investigating cognitive or affective processes that include participants with a Depersonalisation Disorder (or Depersonalisation-Derealisation Disorder) diagnosis and had a sample size of more than 5 were include in the review. In order to maximise the number of studies included in the review, studies with both adult (aged 18-65) and/or adolescent (aged 13-18) participants were included, as well as studies with other comorbid disorders. Grey literature (eg conference papers, unpublished PhD dissertations etc) and non-English papers were excluded from this review.

Papers produced by first searches in the databases were exported into the reference management software EndNote. Duplications were automatically identified within EndNote, as well as manually identified by the author. After removal of duplications, initial searches produced 3349 papers (see [Figure 1](#)), and a further 2887 papers were excluded due to being unrelated to scope of review after screening of titles. After abstract and full-text screening based on the inclusion and exclusion criteria above, 23 papers were selected for full text review. During this stage, the majority of the papers were excluded due to not being related to cognitive or affective processes (n=158), or

not being specific to the DPD population (n=277). Other reasons for exclusion include: non-English papers (n=20), grey literature (n=13), and having a sample size of less than 5 (n=10).

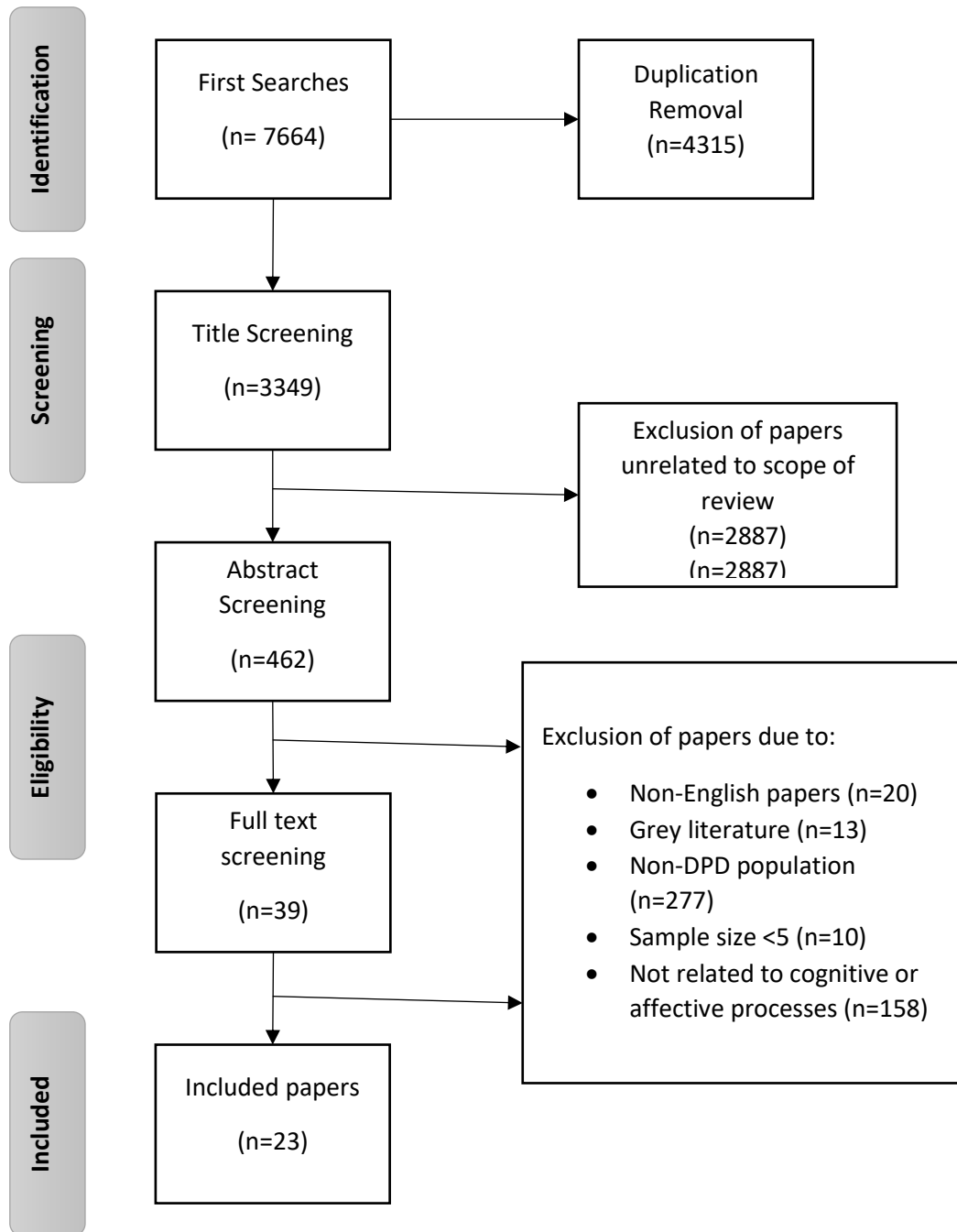


Figure 1: PRISMA¹ flow chart of article selection process through the systematic review

¹ PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses (www.prisma-statement.org)

The screening process was completed by two reviewers independently, with the author completing 100% of the data screening and rating, and the second-rater completing 50% of the data screening and rating. The quality of the studies was rated using the NHLBI Quality Assessment of Case-Control Studies (National Heart, Lung, and Blood Institute, 2019; see Appendix A for the rating tool). This tool was selected as it is well-structured, easy to use, and identified as an acceptable tool for assessing the methodological quality of case-control studies (Ma et al., 2020).

Results

Following full-text screening, 23 papers were selected to be included in this review. Of the 23, 6 papers related to investigations of cognitive abilities (see [Table 1](#)), and 17 related to investigations of affective processing. Among the papers related to affective processing, these can be further categorised into papers relating to impact of emotion on cognition (n=4; see [Table 2](#)), papers relating to alexithymia, emotional recognition and subjective experience of emotion (n= 7; see [Table 3](#)), and papers relating to neurophysiological responses to emotional stimuli (n=8; see [Table 4](#)). Due to the diverse nature of the papers included, a narrative synthesis of the main findings of included papers was conducted and is presented in the next section.

Participants

A total of 855 participants were included in 23 studies. This was made up of 358 (196 males, 152 females, mean age= 30.4 years) participants with DPD, 90 participants (49 males, 41 females, mean age = 36.0 years) with other mental health problems (eg anxiety disorders, borderline personality disorder, autism spectrum disorder), and 407 (213 males, 194 females, mean age= 31.1 years) healthy controls.

Of the 23 studies included, 9 studies provided additional information about the educational level of participants included. This was usually measured by number of years in education, although 4 studies provided their own rating. All studies including information about participants' educational levels indicated no significant differences between healthy controls and DPD participants. All but one study (Simeon et al., 2003) included information about the ethnicity of participants included, with 82% of the 78 included participants (56 DPD, 22 HC) being of a Caucasian background (n=64), 5% African-American (n=4), 8% Hispanic (n=6) and 5% Asian (n=4).

Measures of cognitive abilities

Across the 6 included studies that investigated cognitive abilities in DPD participants, cognitive abilities were measured using a variety of standardised neuropsychological batteries or selection of tests. General cognitive abilities were measured using the Wechsler Adult Intelligence Scale, Third and Revised (WAIS-III/R; Wechsler, 1981) editions. Verbal and visual memory abilities were measured on the Wechsler Memory Scale, Revised Edition (WMS-R; Wechsler, 1987). Although many of the studies overlapped in investigating specific areas of cognition such as attention or memory, none of the studies overlapped in their choice of neuropsychological test used. Other included neuropsychological tests and their measured cognitive ability include:

- Stroop Colour-Word Test: attention

- Emotional Stroop Test: interference of emotion on attention
- Trail Making Test A&B: attention, visual motor
- Wisconsin Card Sorting Test: set-shifting, mental flexibility
- Facial Recognition Test: visuospatial processing independent of memory
- Vigil's Continuous Performance Test: attention and inhibition
- Spatial Cueing Paradigm: spatial attention
- Paced Auditory Serial Addition Test: working memory, divided attention
- Digit Span with Distraction: selective attention
- Cognitive Reasoning Task: executive functioning

One study (Simeon et al, 2009) measured cognitive abilities using self-report questionnaires, such as the Cognitive Failures Questionnaire (Broadbent et al., 1982). In studies not specifically investigating cognitive abilities, 3 studies used the National Adult Reading Test (NART; Nelson, 1982) to determine and match general intelligence of participants.

Measures of affective abilities

Of the 17 studies investigating affective abilities of DPD participants, most studies conducted task-specific behavioural tasks, usually after being exposed to emotional stimuli such as facial expressions from the Benton & Van Allen Test of Facial Recognition (Benton, Sivan, deS Hamsher, Varney, & Spreen, 1994), pictures of eyes from the Reading the Mind in the Eyes test (Baron-Cohen et al, 2001), pictures from the International Affective Picture System (IAPS; Lang & Bradley, 1999) or audio clips from the International Affective Digitalised Sounds (IADS; Bradley & Lang, 2007).

Affect was also measured using self-report questionnaires, including the Multidimensional Anger Inventory (Siegel, 1986), Affect Intensity Measure (Larsen et al., 1986), Emotional Quotient (Muncer & Ling, 2006) and Interpersonal Reactivity Index (Davis, 1980b). In particular, alexithymia was measured using the Toronto Alexithymia Scale (TAS-20; Taylor et al., 1988).

Clinical Outcome Measures for Depersonalisation, Low Mood and Anxiety

Across the included studies, 16 studies used self-report questionnaires to measure dissociative and/or depersonalisation symptoms, most commonly the Dissociative Experience Scale (n=13; DES; Bernstein & Putnam, 1986) and/or the Cambridge Depersonalisation Scale (n=12; CDS; Sierra & Berrios, 2000). 10 studies used structured clinical diagnostic tools, such as the Structured Clinical Interview for Dissociative Disorders (SCID; Steinberg, 1993) and/or Present State Examination (PSE; Wing, 1980) by psychiatrists to determine the diagnosis of DPD in the patient group. The CDS was occasionally used as a supplementary diagnostic tool for DPD, as scores above 70 on the CDS has

been found to be discriminatory of DPD (Sierra & Berrios, 2000). The Peritraumatic Dissociative Experiences Questionnaire (Marshall et al., 2002) was used in one study (Giesbrecht et al, 2010) to supplement the use of both the CDS and DES outcome measures.

Self-report clinical outcome measures were also used in 15 studies to measure levels of low mood and anxiety, such as the Beck Depression Inventory (n=12; BDI; Beck et al., 1988), Beck Anxiety Inventory (n=4; BAI; Beck et a., 1988), Spielberger State and Trait Anxiety Inventory (n=7; STAI; Spielberger, 1983); Hamilton Rating Scale for Depression (n=1; Hamilton, 1960), Hamilton Rating Scale for Anxiety (n=1; Hamilton, 1959), and the Profile of Mood States (n=1; (C. D. Spielberger, 1972). Some studies also included the use of the Childhood Trauma Questionnaire (n=3; CTQ; Bernstein et al., 2003) to understand the clinical background of the participants.

Inter-rater reliability

Both raters had an inter-rater reliability of 100% and 86.96% for the process of screening studies to be included, and rating included studies respectively. After screening and rating independently (see Table 5 for a table of quality ratings for included studies), discrepancies were resolved through discussion, without needing the involvement of a third-party for mediation.

Table 1:

List of included papers investigating cognitive abilities in people with DPD (n=6)

Paper	n	Target measure	Test/Outcome used	Main findings
Adler et al (2014)	16 DPD, 17 HC	Altered selective spatial attention - enhanced cued target processing (RT benefits) - suppression of uncued target processing (RT costs) - total attention directing effect= RT benefits+costs	Clinical Measures: - BDI/STAI/CDS Spatial Cueing paradigm - 2 conditions of detection and discrimination - <i>Discrimination</i> : discriminate between these two types of events and only respond to stimulus defined as the target - <i>Detection</i> : both types of event stimuli were defined as targets and had to be detected without discrimination	<ul style="list-style-type: none"> No differences between DPD and HC in terms of response accuracy Differences between DPD and HC were only found in discrimination condition (higher cognitive load), as DPD had smaller total attention directing effect due to RT costs (HC RT costs in Dis>Det, while DPD RT costs in Dis=Det)
Guralnik et al (2007)	21 DPD, 17 HC	Early information processing, memory and attention	<ul style="list-style-type: none"> WAIS-R/WAIS-III <ul style="list-style-type: none"> - verbal IQ - performance IQ - verbal comprehension - perceptual organisation - working memory - processing speed WMS-R <ul style="list-style-type: none"> - verbal memory - visual memory Paced Auditory Serial Addition Test <ul style="list-style-type: none"> - working memory - divided attention Digit Span with Distraction test <ul style="list-style-type: none"> - selective attention Clinical Measures <ul style="list-style-type: none"> - Dissociative Experiences Scale (DES) - Hamilton Rating Scale for Depression - Hamilton Rating Scale for Anxiety 	<p>WAIS-R/WAIS-III</p> <ul style="list-style-type: none"> No significant differences in full, verbal or performance IQ Significantly slower processing speed Slower perceptual organisation (p=0.08; large effect size) <p>WMS-R</p> <ul style="list-style-type: none"> poorer immediate visual and verbal recall, but not delayed memory <p>PASAT/DSTD</p> <ul style="list-style-type: none"> no group differences in working memory and selective attention <p>Dissociation severity (DES Scores)</p> <ul style="list-style-type: none"> negatively correlated with full-scale IQ, processing speed and distractibility positively related to number of errors on DSTD not mediated by anxiety/depression

Guralnik, Scheidler & Simeon (2000)	15 DPD, 15 HC	General cognitive profile, particularly attention and memory	<ul style="list-style-type: none"> • WAIS-R - verbal, performance & general intelligence • WMS-R - verbal & visuo-spatial memory • Stroop Colour-Word Test - attention • Emotional Stroop task - interference of emotional material with selective attention and memory • Trail Making Tests A & B - attention, visual-motor and sequencing • Wisconsin Card Sorting Test - conceptualisation, executive functioning and set shifting • Facial Recognition Test - visuo-spatial processing independent of memory • Vigil's Continuous Performance Test - attention and impulsivity 	<p>WAIS-R</p> <ul style="list-style-type: none"> • No group differences in IQs • Significantly poorer in Block Design test, indicating impairments in visual perception and visual spatial reasoning with both 2- and 3-dimensional stimuli. <p>WMS-R</p> <ul style="list-style-type: none"> • Significantly worse in general and visual memory summary measures • Significantly worse on logical memory, figural and visual paired memory subtests, indicating a decrease in short-term verbal memory capacity when presented with an overload of information <p>Stroop (Colour-Word/emotional/learning)</p> <ul style="list-style-type: none"> • No group differences in interferences effects for both colour-word and emotional conditions • Superior recall for words related to DP, and also for negative words & overall recall but not significant after correction <p>TMT/WCST/FRT</p> <ul style="list-style-type: none"> • No group differences reported <p>VCPT</p> <ul style="list-style-type: none"> • Significantly more affected by visual distraction, especially in omission response
Lambert et al (2001)	28 DPD, 13 HC	Visual imagery	<p>Clinical Measures:</p> <ul style="list-style-type: none"> - BDI/BAI/DES/DES-taxon (pathological dissociation) <p>Visual Imagery Measures:</p> <ul style="list-style-type: none"> - Vividness of Visual Imagery Questionnaire (VVIQ)* - Vividness of Movement Imagery Questionnaire (VMIQ) - Visual Object and Space Perception (VOSP)** <p>*validity is questioned</p> <p>**subset of DPD only (n=10)</p>	<p>Clinical Measures</p> <ul style="list-style-type: none"> • Significantly higher on DES, BDI and BAI <p>VVIQ/VMIQ</p> <ul style="list-style-type: none"> • DPD patients scored as 'poor' visualisers while HC in 'normal' range • Significant differences in VVIQ/VMIQ & VVIQ-P/VMIQ-self scores; • VVIQ-Obj/VMIQ-other scores approaching significance • VVIQ, VVQI-P, VVIQ-Obj & VMIQ self-associated with DES-taxon scores • Depression significantly contributes to poor visual imagery as a potential mediator <p>VOSP</p> <ul style="list-style-type: none"> • No group differences on all subtests, indicating normal levels of visual perception
Lemche et al (2016)	9 DPD, 12 HC	Cognitive load (attention & working memory)	<p>Clinical Measures: CDS>70</p> <p>Combined Stroop and negative priming tasks in neutral control and Stroop/negative priming active probe condition</p> <p>EDA, fMRI & BOLD data was also collected</p>	<ul style="list-style-type: none"> • DPDR group made fewer correct responses, greater variability in response-delays • No gross impairments in selective attention, cognitive inhibition and working found in DPD group • Slight NP deficits in reduced short-term memory, higher distractibility, and inability to suppress stress-related arousal states under cognitive task

Simeon et al (2009) 46 DPD, 21 PTSD, 35 HC Relationship between alexithymia, absorption and everyday cognitive failures in DPD

Questionnaires:

- CDS/DES
- Toronto Alexithymia Scale (TAS-20)
- Tellegen Absorption Scale (TAS)
- Cognitive Failures Questionnaire (CFQ)
- Childhood Trauma Questionnaire (CTQ)

- DPD & PTSD showed similar levels of cognitive failures in everyday life, and were significantly worse than healthy controls
- DPD showed significantly higher levels of alexithymia compared to both groups, with particular deficits in identifying feelings across dx
- Alexithymia was highly discriminatory of DPD diagnosis, distinguishing it from both other groups, and was the sole predictor of depersonalisation scores

Table 2:

List of included papers investigating impact of emotion on cognitive abilities in DPD (n=4)

Authors	n	Stimuli	Test	Findings
Giesbrecht et al (2010)	14 DPD 14 HC	Emotional film clip	Questionnaires: <ul style="list-style-type: none"> - DES/CDS/CTQ - BDI/BAI - Peritraumatic Dissociative Experiences Questionnaire (PDEQ) - Profile of Mood States (POMS) Measures of Memory: <ul style="list-style-type: none"> - subjective memory fragmentation - free recall of video clip - objective memory fragmentation Physiological measure: <ul style="list-style-type: none"> - skin conductance 	Questionnaire: <ul style="list-style-type: none"> • DPD scored higher on BAI, BDI, CTQ (emotional abuse subscale) • peritraumatic dissociation and anxiety increased in HC but remained constant in DPD Measures of Memory: <ul style="list-style-type: none"> • DPD had significantly worse subjective and objective memory fragmentation • No sig diff for free recall Physiological measure: <ul style="list-style-type: none"> • DPD showed heightened baseline SC levels, mediated by comorbid anxiety • DPD had overall flatter response over time to emotional stimuli, as compared to HC rising pattern, may be explained by a phasic selective inhibitory response to emotional stimuli • DPD had fast initial response to peak, may be driven by heightened alertness at baseline • No difference in terms of peak amplitude • DPD showed lack of recovery after clip offset
Lawrence et al (2012)	16 DPD 15 AS 32 HC	Reasoning problems (neutral vs emotional)	Clinical Measures: <ul style="list-style-type: none"> - DES/NART Conditional Reasoning Task <ul style="list-style-type: none"> - 48 (3x16) reasoning problems divided into three groups: no extra statements, additional statements (highlights exception to given premise; ↓ valid inferences), & alternative statements (highlights different antecedent may result in same consequence; ↓ fallacies) - Each group of 16 was divided into 4 sets of logical forms, and 3 has neutral material, and the 1 had emotional content (↑ fallacies) 	<ul style="list-style-type: none"> • Both AS & DPD group showed reduced suppression of valid inferences when additional statements are provided (less likely to draw on exceptions to the given premise when reasoning), suggesting difficulties with mental flexibility and perseverativeness • AS showed less marked suppression effect when alternative statements are provided. • There were within-group differences in ASD & DPD for reasoning with emotional vs neutral content, but no inter-group differences in fallacious inferences made with emotional content, although this may not be a robust enough difference

Medford et al (2006)	10 DPD 10 HC	Reading sentences	<p>Clinical Measures:</p> <ul style="list-style-type: none"> - BDI/BAI - NART <p>Behavioural Task</p> <ul style="list-style-type: none"> - Participants were presented with 41 sentences (2x21 + 8 filler) with emotionally aversive target words and affectively neutral words respectively. - Encoding: Asked to read sentences quietly - Recognition: target word recognition (aversive vs neutral) and embedded word recognition (aversive context vs neutral context) - fMRI data was also collected during behavioural task 	<ul style="list-style-type: none"> • Generally, emotional enhancement of recognition memory was absent in DPD, although this effect was only present for contextual emotional enhancement (embedded neutral words in aversive sentences). • No neuroimaging difference was observed in DPD brains when encoding aversive and neutral sentences, in contrast to controls who showed activation in anterior cingulate cortex and precuneus • In content task, right precentral gyrus (non-specific area for motor/working memory) was activated for both aversive and neutral words in DPD, which was not suggestive of any emotion enhancement effect. • In context task, DPD performed better recognising words in neutral contexts, demonstrating lack of emotional enhancement. However, right ventral striatum (associated with emotional processing) was activated in response to embedded words in emotional contexts • Significant difference in behavioural performance in emotional content task not being reflected in neural activation patterns may be explained by the successful use of cognitive strategy for both emotional and neutral words
Montagne et al (2007)	12 DPD 20 HC	Emotive story	<p>Questionnaires</p> <ul style="list-style-type: none"> - BDI/CDS/DES - NART - Benton & Van Allen Test of Facial Recognition <p>Emotional Memory Task</p> <ul style="list-style-type: none"> - A story about a boy who suffers a terrible car accident and rushed to a hospital is presented to participants in 11 picture slides and accompany text - Memory for central and peripheral aspects of emotional and neutral information is tested without prior warning 1 week after the presentation with a 76-item MCQ 	<ul style="list-style-type: none"> • No group effects between DPD and HC were found, and this was not due to differences in NART IQ • Central information was found to be better remembered than peripheral information, although peripheral information was remembered more accurately when this information was emotional compared with neutral.

Table 3:

List of included papers investigating alexithymia, emotional recognition, and experience of emotion in DPD (n=6)

Authors	n	Stimuli	Test(s)	Findings
Lawrence et al (2007)	16 DPD 48 HC	Reading emotive diary extract/ Actors's eyes	<p>Clinical Measures</p> <ul style="list-style-type: none"> • DES/CDS/BDI/BAI <p>Empathy Measures</p> <ul style="list-style-type: none"> • <i>Emotional Quotient (EQ)</i> to measure 3 factors: <ul style="list-style-type: none"> - cognitive empathy - emotional reactivity - social skills • Excerpt of <i>Interpersonal Reactivity Index</i> measuring personal distress <p>Physiological Arousal Measure</p> <ul style="list-style-type: none"> • Rate of speech in Counting Task after emotive diary extract • Trait Task <ul style="list-style-type: none"> - adapted Trait Adjective Checklist by reducing down to 75 traits from 159 - self-endorse traits that are related to self - endorse traits that are related to protagonist of vignette <p>Mental State Labelling</p> <ul style="list-style-type: none"> • <i>Reading the Eyes in the Mind Task</i> - look at a photograph of an actor's eyes & choose one of four words to match the emotion that match 	<ul style="list-style-type: none"> • DPD reported less empathy (EQ scores; mostly noticeably in social skills factor) and less egocentric feelings of personal distress (extracted IRI scores). • Reduced personal distress from other's emotional state in DPD also supports the idea that the emotional numbing may to some extent be specific to external or social stimuli. • There was also a lack of congruent physiological arousal in response to emotional narratives (increased speech rate after a sad vignette, and decreased speech rate after a happy vignette). • However, increase in speech rate after a sad vignette may reflect anxiety (although this doesn't fit with reduced self-reported personal distress); or a failure in interoceptive processing leading to self-reports of 'emotional numbing' • However, DPD were as accurate as controls in labelling mental states from photographs of eyes, suggesting no deficit in emotional recognition and the cognitive aspect of empathy • DPD had more overlap between mental representations of the self and target, suggesting increased self-focus when attributing affective states to others, specifically in response to negative affective states
Lemche et al, 2013	9 DPD 12 HC	Facial expression (Happy/sad)	<p>Behavioural Task</p> <ul style="list-style-type: none"> • 10 faces where presented with varying happy and sad facial expressions of emotion in 0-50-100% gradations of intensity • Faces were presented in two implicit event-related tasks, where participants were required to indicate the sex of the face <p>Questionnaire:</p> <ul style="list-style-type: none"> • CDS/DES/BDI/STAI • Screening for Somatoform Disorders (SOMS) • Toronto Alexithymia Scale (TAS-20) with 3 dimensions: <ul style="list-style-type: none"> - Identification of Feelings - Description of Feelings - External-Concrete cognitive style 	<ul style="list-style-type: none"> • Total TAS-20 score significantly predicts DPD dx, suggesting alexithymia severity contributes significantly to the clinical diagnosis of DPD. • The abnormal neuroactivity in the left globus pallidus externus and left dorsal anterior cingulate predicts the emotional processing of happiness, and sadness respectively, suggesting that these regions are associated with interoception, monitoring and reflection of internal states

Montagne et al (2007)	13 DPD 33 HC	Facial expression (Happy/sad/anger/disgust/fear/surprise)	<p>Questionnaires</p> <ul style="list-style-type: none"> - BDI/CDS/DES - NART - Benton & Van Allen Test of Facial Recognition <p>Emotional Recognition Task</p> <ul style="list-style-type: none"> - 4 actors (2M2F) mimicked 6 emotional expressions (anger, disgust, fear, happiness, sadness and surprise) and a neutral expression - 8x24 videos of the actors' neutral morphing into the 6 expressions, with 10% increase in emotional intensity were presented - Pts were asked to label the emotion among 6 forced-choice options, with no time restriction 	<p>Emotional Recognition Task</p> <ul style="list-style-type: none"> • No significant differences between DPD and HC, with both group performances within normal range. • Bonferroni-corrected post-hoc tests showed DPD being significantly less sensitive than HC to recognising the emotion anger, regardless of depressive symptoms.
Sierra et al (2006)	16 DPD 15 Anx 15 HC	Facial expressions (happy/disgusted)	<p>Questionnaires:</p> <ul style="list-style-type: none"> - CDS/BDI/STAI <p>Behavioural Task</p> <ul style="list-style-type: none"> - 24 stimuli blocks (12x2) of happy/disgusted facial expression clips were alternated in gender and presented to participants - Participants were asked to label the emotional expression in a 6-choice MCQ (surprise, happiness, anger, disgust, sadness and fear) - Skin conductance was measured throughout the task 	<ul style="list-style-type: none"> • Patients in anxiety group were found to have heightened autonomic responses to disgust expressions as compared to DPD and HC • DPD did not have raised SCR despite reporting similar levels of subjective anxiety in outcome measures, suggesting presence of DP has blunting effect on autonomic reactivity • Negative correlation between CDS scores and SCR to disgust expressions • DPD did not differ in emotion recognition of disgust, but rated them as less intense than anx and HC groups
Simeon et al (2003)	56 DPD 22 HC	N/A	<ul style="list-style-type: none"> - DES - STAI - Multidimensional Anger Inventory - Affect Intensity Measure (29 DPD, 15 HC) - Boundary Questionnaire (28 DPD, 15 HC) 	<ul style="list-style-type: none"> • DPD experienced significantly greater anxiety, anger and negative affect intensity, but there were no differences in positive or total affect intensity • DPD had thinner boundaries, meaning they were less able to perceive emotional and cognitive categories • Severity of dissociation and depersonalisation were more strongly related to anxiety than anger • Anxiety was the strongest predictor of depersonalisation and pathological dissociation • Positive affect intensity was not significantly blunted in DPD
Simeon et al (2009)	46 DPD, 21 PTSD, 35 HC	N/A	<ul style="list-style-type: none"> - CDS/DES - Toronto Alexithymia Scale (TAS-20) - Tellegen Absorption Scale (TAS) - Cognitive Failures Questionnaire (CFQ) - Childhood Trauma Questionnaire (CTQ) 	<ul style="list-style-type: none"> • DPD & PTSD showed similar levels of cognitive failures in everyday life, and were significantly worse than healthy controls • DPD showed significantly higher levels of alexithymia compared to both groups, with particular deficits in identifying feelings across dx • Alexithymia was highly discriminatory of DPD diagnosis, distinguishing it from both other groups, and was the sole predictor of depersonalisation scores

Table 4:

List of included papers investigating neurophysiological responses to emotional stimuli in DPD (n=8)

Authors	n	Stimuli	Test	Findings
Giesvrech et al (2010)	14 DPD 14 HC	Emotional film clip	<p>Questionnaires:</p> <ul style="list-style-type: none"> - DES/CDS/CTQ - BDI/BAI - Peritraumatic Dissociative Experiences Questionnaire (PDEQ) - Profile of Mood States (POMS) <p>Measures of Memory:</p> <ul style="list-style-type: none"> - subjective memory fragmentation - free recall of video clip - objective memory fragmentation <p>Physiological measure:</p> <ul style="list-style-type: none"> - skin conductance 	<p>Questionnaire:</p> <ul style="list-style-type: none"> • DPD scored higher on BAI, BDI, CTQ (emotional abuse subscale) • peritraumatic dissociation and anxiety increased in HC but remained constant in DPD <p>Measures of Memory:</p> <ul style="list-style-type: none"> • DPD had significantly worse subjective and objective memory fragmentation • No sig diff for free recall <p>Physiological measure:</p> <ul style="list-style-type: none"> • DPD showed heightened baseline SC levels, mediated by comorbid anxiety • DPD had overall flatter response over time to emotional stimuli, as compared to HC rising pattern, may be explained by a phasic selective inhibitory response to emotional stimuli • DPD had fast initial response to peak, may be driven by heightened alertness at baseline • No difference in terms of peak amplitude • DPD showed lack of recovery after clip offset
Lawrence et al (2007)	16 DPD 48 HC	Reading emotive diary extract/ Actors's eyes	<p>Clinical Measures</p> <ul style="list-style-type: none"> • DES/CDS/BDI/BAI <p>Empathy Measures</p> <ul style="list-style-type: none"> • <i>Emotional Quotient (EQ)</i> to measure 3 factors: <ul style="list-style-type: none"> - cognitive empathy - emotional reactivity - social skills • Excerpt of <i>Interpersonal Reactivity Index</i> measuring personal distress <p>Physiological Arousal Measure</p> <ul style="list-style-type: none"> • Rate of speech in Counting Task after emotive diary extract • Trait Task <ul style="list-style-type: none"> - adapted Trait Adjective Checklist by reducing down to 75 traits from 159 - self-endorse traits that are related to self - endorse traits that are related to protagonist of vignette <p>Mental State Labelling</p> <p><i>Reading the Eyes in the Mind Task</i> - look at a photograph of an actor's eyes & choose one of four words to match the emotion that match</p>	<ul style="list-style-type: none"> • There was a lack of congruent physiological arousal in response to emotional narratives (increased speech rate after a sad vignette, and decreased speech rate after a happy vignette). • However, increase in speech rate after a sad vignette may reflect anxiety (although this doesn't fit with reduced self-reported personal distress); or a failure in interoceptive processing leading to self-reports of 'emotional numbing' • However, DPD were as accurate as controls in labelling mental states from photographs of eyes, suggesting no deficit in emotional recognition and the cognitive aspect of empathy • DPD had more overlap between mental representations of the self and target, suggesting increased self-focus when attributing affective states to others, specifically in response to negative affective states

Lemche et al (2007; 2008; 2013a; 2013b)	9 DPD 12 HC	Facial expression (Happy/sad)	<p>Behavioural Task</p> <ul style="list-style-type: none"> • 10 faces were presented with varying happy and sad facial expressions of emotion in 0-50-100% gradations of intensity • Faces were presented in two implicit event-related tasks, where participants were required to indicate the sex of the face <p>Questionnaire:</p> <ul style="list-style-type: none"> • CDS/DES/BDI/STAI • Screening for Somatoform Disorders (SOMS) • Toronto Alexithymia Scale (TAS-20) with 3 dimensions: <ul style="list-style-type: none"> - Identification of Feelings - Description of Feelings - External-Concrete cognitive style 	<ul style="list-style-type: none"> • As emotional intensity (both happy & sad) in facial expression increases, DPD showed BOLD signal decreases in hypothalamus and amygdala, while HC showed opposite trends. This may be a neural correlate of the inexperience of emotion. • only DPD showed negative correlations between autonomic and neural responses in dorsal prefrontal cortex to these stimuli, evoking increased autonomic activity, suggesting that this abnormal increase in PFC to emotional stimuli may be a mechanism involved in the emotional detachment <ul style="list-style-type: none"> - DPD has increased dl-PFC response to facial expressions, which invokes inhibitory neural responses. HC exhibited anterior-PFC activations, responsible for 'release' functions instead of inhibitory - DPD showed earlier peak +/- haemodynamic (BOLD) responses post-stimuli, and this is +ve correlated with discriminatory skin conductance levels - These findings suggest a faster perceptual processing of emotional stimuli, before emotional suppression. • The abnormal neuroactivity in the left globus pallidus externus and left dorsal anterior cingulate predicts the emotional processing of happiness, and sadness respectively, suggesting that these regions are associated with interoception, monitoring and reflection of internal states • Co-involvement of affective regions of the pain neuromatrix, we observed insular and ACC involvement, but not that of other regions of the pain matrix. • Anterior insula, ACC and orbital gyrus support the assumption of greatest group differences in interoceptive regions, and regions involved in emotion regulation <ul style="list-style-type: none"> - Strongest predictors of DPRD dx is depression severity followed by somatization severity - Discriminatory brain regions for somatization suggests that somatization could follow neural representations of interoception
Medford et al (2016)	14 DPD (4 dna) 25 HC	IAPS (aversive/neutral pictures)	<p>Behavioural Task</p> <ul style="list-style-type: none"> - Emotional vs neutral block-design fMRI paradigm, utilising stimuli from the International Affective Picture System (IAPS). - They viewed alternating blocks of neutral and aversive images and asked to determine if the scene was indoors/outdoors, allowing implicit emotional processing. - Neuroimaging (fMRI BOLD signal) and autonomic (SCLs) data were collected during behavioural task <p>Pharmacological Treatment</p> <ul style="list-style-type: none"> - Patients were treated with lamotrigine after first fMRI measurement, to reach a target dose in the range of 200-400mg/day <p>Questionnaires</p> <ul style="list-style-type: none"> - CDS/BDI/STAI 	<ul style="list-style-type: none"> • DPD were less autonomically reactive than healthy controls, although this effect was not specific to responses to emotional stimuli • Improvements in clinical state as supported by decreased CDS scores were not associated with any significant changes in SCR variables, whether within or between subjects. However, many improved participants (except 1) were still scoring above clinical threshold on the CDS • In contrast, fMRI data shows clear association in changes in brain activation patterns and improvements in DPD symptoms. • In response to aversive stimuli, DPD show activation in right lateral PFC, bilateral primary visual cortex, bilateral ACC and left medial PFC. <ul style="list-style-type: none"> - activation of visual cortex thought to reflect modulation of sensory cortex by back projection from areas involved in emotional processing • Visual cortex was significantly more active at T2 than T1, suggesting a reduction in CDS score is associated with increased modulation of sensory cortex by emotional processing • Right BA47 found to be preferentially activated in response to aversive images in T1 for DPD pts, and in T2 for non-improvers, suggesting that the area is a critical region for the 'top-down' inhibition of emotional responses in DPD. <ul style="list-style-type: none"> - same area has been implicated for voluntary regulation of emotion in HC, suggesting right BA47 is recruited when inhibiting emotional responses regardless of volition

				<ul style="list-style-type: none"> • Activation of left anterior insular (related to emotion & interoceptive bodily sensation) seen in normal controls in T1 and improved DPD pts in T2, but was lacking in DPD in T2 and non-improvers in T2
Michal et al (2013)	22 DPD 15 HC	IADS (positive/negative/neutral sounds)	<p>Questionnaires:</p> <ul style="list-style-type: none"> • DES/CDS/CTQ/BDI • Mindful Attention Awareness Scale (MAAS) <p>Behavioural Task:</p> <ul style="list-style-type: none"> • Resting base electrodermal and heart rate were measured • 5 sets (neutral, med negative, high negative, med positive, high positive) of 4x6s sounds were presented • Participants listened to auditory stimuli (from International Affective Digitized Sounds) with eyes closed in random order • Volume was individually adjusted, and autonomic physiological response was measured throughout the task • Participants were exposed to stimuli in 2 conditions: <ul style="list-style-type: none"> - listen to the sounds and be attentive to the emotional scenarios - breathe mindfully (pay attention to bodily sensations) while listening 	<ul style="list-style-type: none"> • DPD & HC matched for severity of dep and anxiety, showed similar levels of traumatic childhood experiences and dissociative amnesia, but DPD has lower dispositional mindfulness. • DPD & HC had similar resting rates of SCR and HR, but DPD had more non-specific SCR • Although DPD patients rated unpleasant sounds as less unpleasant than HC and normative ratings, they showed stronger electrodermal responses to emotional sounds than HC • SCR amplitudes depended on emotional valence and arousal for DPD, while HC showed no such modulation • Mindful breathing led to subjective increase in feeling grounded in both groups, and decreased DP intensity in DPD, and also enhanced differential electrodermal responses to med/high emotional sounds.
Phillips et al (2001)	6 DPD 10 OCD 6 HC	Pictures (disgusting/neutral)	<p>Questionnaires:</p> <ul style="list-style-type: none"> - DES/BDI/STAI <p>Behavioural Task</p> <ul style="list-style-type: none"> - 5 blocks of 10 pictures (all aversive/disgusting, or all neutral) were presented to participants in an fMRI scanner - Subjects indicated if the scene was indoor or outdoors to facilitate implicit emotional processing - Subjective emotional ratings of images were done after the task, as images were re-presented and rated. 	<p>Subjective Ratings</p> <ul style="list-style-type: none"> • HC & OCD had significantly higher rating for all dimensions (fear/anxiety/disgust) in aversive pictures • DPD did not rate aversive scenes significantly differently from neutral scenes <p>fMRI Findings</p> <ul style="list-style-type: none"> • The insula, implicated in perception of disgust, was activated in HC & OCD when viewing aversive scenes, but not in DPD • However, the insula was significantly more activated in DPD as compared to HCs when shown neutral scenes • Occipito-temporal (visual) cortex, implicated in perception of fear and disgust, were activated in HC & OCD, suggesting heightened visual attention and processing induced by aversive stimuli • HCs showed greater activation in bilateral anterior cingulate gyri (associated with experience of low mood) and left posterior cingulate gyrus (emotional appraisal) compared to DPD • Both OCD (BA 44) and DPD (BA 47) groups showed a significant activation in the right prefrontal cortex (appraisal of emotional stimuli & regulation of emotional experience) in response to aversive scenes • DPD demonstrate an inverse functional relationship between the left insula and right ventral prefrontal cortex during aversive scenes, suggesting a greater regulation or 'inhibition' by the right ventral frontal cortex of the normal insular response to emotional stimuli

Sierra et al (2006)	16 DPD 15 Anx 15 HC	Facial expressions (happy/disgusted)	<p>Questionnaires:</p> <ul style="list-style-type: none"> - CDS/BDI/Spielberger's trait and state anxiety scale <p>Behavioural Task</p> <ul style="list-style-type: none"> - 24 stimuli blocks (12x2) of happy/disgusted facial expression clips were alternated in gender and presented to participants - Participants were asked to label the emotional expression in a 6-choice MCQ (surprise, happiness, anger, disgust, sadness and fear) - Skin conductance was measured throughout the task 	<ul style="list-style-type: none"> • Patients in anxiety group were found to have heightened autonomic responses to disgust expressions as compared to DPD and HC • DPD did not have raised SCR despite reporting similar levels of subjective anxiety in outcome measures, suggesting presence of DP has blunting effect on autonomic reactivity • Negative correlation between CDS scores and SCR to disgust expressions • DPD did not differ in emotion recognition of disgust, but rated them as less intense than anx and HC groups
Sierra et al (2002)	15 DPD 11 Anx 15 HC	IAPS (pleasant/unpleasant/neutral pictures)	<p>Questionnaire:</p> <ul style="list-style-type: none"> - CDS/BDI/STAI <p>Behavioural Task</p> <ul style="list-style-type: none"> - 15 (3x5) pictures from IAPS were selected and categorised into neutral, pleasant and unpleasant valence - Participants were presented the pictures in a randomised counter-balanced order in 2 blocks - After showing the picture for 30s, there is a 30s interval between pictures, and pts are asked to rate the picture on valence and arousal - Skin conductance is measured through-out 	<ul style="list-style-type: none"> • There was no significantly differential SCR in DPD to unpleasant stimuli, as compared to pleasant and neutral stimuli, in contrast with HC and Anx groups who showed higher SCR to unpleasant stimuli • Reduced SC baseline and fewer non-specific fluctuations suggest a tonic inhibitory mechanism • DPD had fewer measurable responses to the unpleasant stimuli, and when a response was showed, it had significantly lower amplitude, suggesting phasic inhibitory mechanisms • DPD and Anx had higher subjective anxiety than HC, and shorter SCR latency (response time) to nonspecific (physical) stimuli, suggesting increased state of arousal/alertness • Only DPD showed smaller SCR, and delay in response to unpleasant pictures, suggesting an inhibitory response to emotional processing of unpleasant stimuli

Table 5:

Quality ratings of included papers based on the NIH Quality Assessment of Case-Control Studies

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Quality Rating
Adler et al (2014)	Y	Y	N	Y	Y	Y	CD	NR	N	Y	NR	N	2 Fair
Guralnik et al (2000)	Y	Y	N	Y	Y	Y	Y	NR	CD	Y	NR	Y	3 Good
Guralnik et al (2007)	Y	Y	N	NR	NR	Y	Y	NR	CD	N	NR/CD	Y	2 Fair
Lemche et al (2016)	Y	Y	N	CD	Y	Y	CD	NR	CD	Y	Y	Y	2 Fair
Simeon et al (2009)	N	Y	N	CD	Y	Y	NR	NR	CD	N	NR	CD	1 Poor
Lambert et al (2001)	Y	Y	N	NR	NR	Y	N	NR	CD	N	NR	Y	1 Poor
Giesbrecht et al (2010)	Y	Y	N	Y	Y	Y	CD	CD	CD	Y	NR	Y	2 Fair
Hedrick & Berlin (2012)	Y	Y	N	Y	Y	Y	Y	NA	CD	Y	NR	Y	3 Good
Lawrence et al (2007)	Y	Y	N	CD	Y	Y	NA	NR	CD	Y	NR	Y	2 Fair
Lawrence et al (2012)	Y	Y	N	Y	Y	Y	NA	CD	CD	Y	NR	Y	3 Good
Lemche et al (2007)	Y	Y	N	Y	Y	Y	NR	NR	CD	Y	Y	Y	3 Good
Lemche et al (2008)	Y	Y	Y	Y	Y	Y	CD	CD	CD	Y	Y	Y	3 Good
Lemche et al (2013a)	Y	Y	Y	Y	Y	Y	CD	CD	CD	Y	Y	Y	3 Good
Lemche et al (2013b)	Y	Y	N	Y	Y	Y	NR	NR	CD	Y	Y	Y	2 Fair
Medford et al (2016)	Y	Y	N	Y	Y	Y	NR	NR	Y	N	NR	N	1 Poor
Medford et al (2006)	Y	Y	N	NR	Y	Y	NR	NR	CD	Y	NR	Y	3 Good
Michal et al (2013)	Y	Y	N	Y	Y	Y	NR	NR	CD	Y	NR	Y	3 Good
Monde et al (2013)	Y	Y	N	NR	Y	Y	NR	NR	CD	Y	NR	Y	2 Fair
Montagne et al (2007)	Y	Y	N	N	N	Y	N	NR	CD	Y	NR	Y	1 Poor
Phillips et al (2001)	Y	Y	N	N	Y	Y	NR	NR	CD	Y	NR	Y	2 Fair
Sierra et al (2006)	Y	Y	N	N	Y	Y	NR	NR	CD	Y	NR	Y	2 Fair
Sierra et al (2002)	Y	Y	N	N	Y	Y	NR	NR	CD	N	NR	N	1 Poor
Simeon et al (2003)	Y	Y	N	NR	N	Y	NR	NR	CD	Y	NR	N	1 Poor

Discussion

Quality Review

Of the 23 papers included in the review, 8 papers were rated good, 9 papers were rated fair, and 6 papers were rated poor quality based on the NHLBI Quality Assessment Tool for Case-Control Studies (NHLBI, 2019).

Simeon et al (2009) had a lower quality rating due to not providing clear research questions in the write-up, and inconsistent implementation of measures (introducing questionnaires at different time points in the study), resulting in differing sample sizes for some measures. However, given that the study has a sample size that is relatively larger than other studies investigating DPD, this discrepancy in sample size was not felt to significantly impact on the confidence of the findings of the study.

However, Simeon et al (2009) also did not report where and how controls were recruited, and did not provide any information about educational background of participants. Montagne et al (2007) also recruited controls from a different country and culture compared to the participants, which may introduce cultural bias when comparing the two populations. They also used different groups of controls for different tasks. It is also not clear if levels of depression was controlled for amongst participants of Simeon's studies (2003, 2009), especially since depression is a common comorbid condition and can have adverse impacts on affect and cognition (Perini et al, 2019). Over the course of Medford et al's (2016) study, 4 participants dropped out, and a late decision was made to include 2 participants who were on stable low doses of conventional anti-depressants at the first time point, and did not meet original criteria of being medication-free for at least 6 months. These unreported, uncontrolled and inconsistent factors in participants' background may introduce potential confounding factors, and cast doubt on the validity and reliability of their results. However, the produced findings of these studies were generally consistent with the wider body of literature (Lemche et al, 2013; Giesbrecht et al, 2010; Medford et al, 2018), and as such, suggests that any bias that may have been introduced were minimal, and that the overall findings of the above research can be considered within the review with adequate confidence.

On the other hand, Lambert et al (2001) had a poor-quality rating mainly due to the inclusion of a measure (VVIQ) with questionable construct validity within their study, calling in question the confidence of Lambert et al (2001)'s findings about the vividness of people with DPD's ability to visualise. Due to lack of other studies investigating this feature in DPD, it is unclear how reliable these findings are, and should be considered with the above factors in mind.

Cognitive profile

General

Overall, no significant differences in full scale IQs or any subtypes of IQs were found between people with DPD and healthy controls, when tested using standard neuropsychological batteries of tests like the Wechsler Adult Intelligence Scales and the Wechsler Memory Scale (Guralnik et al., 2000, 2007). Despite this, subjective complaints of neuropsychological difficulties were evident in self-report measures: people with DPD rated significantly higher on the Cognitive Failure (Simeon et al., 2009) and the Frontal Behaviour Questionnaire (Hedrick & Berlin, 2012) compared with healthy controls. This pattern of behaviour was observed to be similar to the PTSD population, who also rated significantly higher on the CFQ than healthy controls. This seems to suggest that while cognitive complaints are subjectively experienced, these difficulties may not be underpinned by objective neuropsychological differences.

Visuospatial and attentional abilities

Despite no significant differences in general abilities, there is also some evidence to suggest subtle deficits in visuospatial abilities. Guralnik et al (2000) found that people with DPD performed significantly poorer in the Block Design test compared to healthy controls, suggesting poorer visual perception and visual spatial reasoning abilities. However, Lambert et al (2001) also found that there were no group differences in visual perception, as measured by the Visual Object and Space Perception. This seems to be corroborated by Guralnik et al (2000) who found that DPD participants performed similarly to healthy controls in the Trail Making Tests, which looks at attention, visual-motor and sequencing skills.

Adler et al (2014) also appears to support this finding, as people with DPD did not display significant differences in spatial attention compared to healthy controls. Adler et al (2014) found that people with DPD had a smaller attention load capacity than healthy controls. Guralnik et al (2000) also found that in the Vigil's Continuous Performance Test, people with DPD were significantly more affected by visual distraction, particularly in the omission response. This seems to suggest that people with DPD were particularly susceptible to visual perceptual load due to a smaller spatial attentional capacity, which may in turn lead to increased inattentive blindness to their environment. Reduced levels of attention and perception of their environment may potentially also contribute to the perceived 'unrealness' of the environment, perpetuating feelings of unreality and derealisation.

Interestingly, DPD participants scored as poor visualisers compared to healthy controls on the Vividness of Visual Imagery Questionnaire (VVIQ), which may suggest poor mental imagery and

visuospatial memory (Lambert et al, 2001). This may potentially be explained by the lower experienced quality of their visual environment due to inattention blindness, and hence, poorer visuospatial memory of their environment. Research has also shown that the cognitive ability to generate mental images is overlapped with visual working memory (Albers et al., 2013; Pearson et al., 2015). It is worth noting that the construct validity of the VVIQ has been questioned (Chara & Hamm, 1989), and as such, the confidence of this finding as an indicator of visuospatial abilities should be mitigated (Lambert et al, 2001). Reduced ability to generate mental imagery may serve as a barrier for imagery-based interventions such as Imagery Rescripting, a psychotherapeutic technique often utilised in CBT and other trauma-focused therapies (Holmes et al., 2007).

The seemingly contradictory pool of evidence about the visuospatial abilities of the DPD population seem to suggest that any differences may be subtle, or mediated by a lower spatial attentional capacity and poorer visual working memory. More research should be conducted into the possible reasons for a smaller attentional capacity in people with DPD. One potential explanation may be that perceptual resources may be competing with visual symptoms of depersonalisation, as many describe their vision as being 'flat' or 'grainy'. However, it is still unclear if the reduced attentional capacity is a result of increased attention on visual symptoms, or if visual symptoms may be a result of reduced attention on their environment.

Memory

Similarly, the body of literature seem to indicate some impairments in the general, visual and verbal memory abilities of the DPD population. Guralnik et al (2000) found that DPD participants performed worse on general and visual memory summary measures than healthy controls. They also fared worse on logical memory, figural and visual paired memory subtests, which suggests lower short-term verbal memory capacity when presented with an overload of information (Guralnik et al, 2000). This reflects a similar pattern of DPD participants being more susceptible to cognitive load, and the consequential impact on key cognitive functions such as memory and attention. This seems to be supported by a later finding by Lemche et al (2016), as DPD participants were found to have slight neuropsychological deficits in reduced short-term memory, higher distractibility and inability to suppress stress-related arousal states under cognitive task. Taken together, the results seem to indicate slight but definitive memory difficulties, which may be linked to reduced working memory and attention capacity, resulting in poorer memory and attention during cognitive load. To reduce the cognitive burden on people with DPD, external reminders (for example, written notes or timed alarms) may be recommended to aid recall for important information and/or tasks. Adaptations could also be

made to improve treatment effectiveness, as people with DPD may benefit from more frequent use of repetition and summarising in therapy and writing down of key learnings.

Summary of Cognitive Abilities in DPD

Generally, while there seem to be no significant differences between the cognitive abilities of people with DPD and healthy controls on the surface, indications of distinct sub-normal cognitive abilities in particular domains such as memory, attention, visuospatial abilities and processing speed cannot be ruled out and require further investigation, particularly in relation to reduced working memory, attentional and perceptual capacity.

Subnormal levels of cognitive differences may be explained by mediating factors such as increased focus of attention on distressing symptoms, leading to reduced attention in other aspects of experience and hence poorer encoded memory of experiences. As more perceptual resources are expended on the symptoms of DPD, this can lead to increased awareness and perceived experience of depersonalisation. Conversely, as other aspects of experience are neglected, this may inadvertently lead to poorer attention and memory in everyday functioning. This is in line with the cognitive-behavioural conceptualisation of Depersonalisation Disorder (Hunter et al., 2003), where symptoms of depersonalisation may be maintained or even made worse due to excessive internal self-focus and symptom monitoring. Further research should be conducted on the potential mediating factor of attention direction on the memory, visuospatial and processing abilities of people with DPD.

Another possible explanation for the subnormal levels of cognitive abilities could be DPD patients' lack of confidence in their own cognitive abilities. Meta-cognition, or beliefs about one's own cognition, has been implicated in the maintenance of poorer general memory abilities in people with some anxiety disorders (Ferreri et al., 2011), particularly within the obsessive-compulsive disorder (OCD) population (Nedeljkovic & Kyrios, 2007). Given DPD's overlap with anxiety disorders, more research into the potential effects of negative meta-cognition within the DPD population may be helpful.

Affective profile

Impact of emotion on cognitive abilities

Interestingly, despite their reported experience of emotional numbing, the emotional enhancement effect on episodic memory (Burke et al., 1992; Hamann, 2001) appears mostly intact in the DPD population. Montagne et al (2007) did not find any group differences between DPD participants and healthy controls, in terms of recall of both central and peripheral aspects of an emotional story. Likewise, Giesbrecht et al (2010) did not find any significant differences between

people with DPD and healthy controls for free recall of an emotional video clip. Medford (2006) also found that DPD participants showed greater recall of aversive target words over non-aversive target words, at a level similar to healthy controls. However, DPD participants did not better recall non-aversive embedded words in contextually aversive sentences, unlike their control counterparts. This indicates a lack of memory enhancement for contextually emotional information within the DPD population. This seems to suggest that while the emotional enhancement effects appear mostly intact in the DPD population, the sensitivity of this emotional enhancement may be reduced.

Lawrence et al (2012) also looked into the emotional impact on DPD participants' ability to solve conditional reasoning problems. DPD and ASD participants did not significantly differ in their reasoning ability with emotional and neutral information, unlike healthy controls, suggesting that the emotional stimuli had a lower impact on the decision-making and logical abilities of DPD and ASD participants. However, the difference between DPD participants and healthy controls in reasoning ability under emotional premises did not attain significance. This seems to suggest that while DPD participants have a reduced affective response to emotional premises, this difference is mild compared to healthy controls. This seems to fit with the trend of other sub-normal cognitive abilities within the DPD population. In general, regular emotional modulation on cognitive abilities appear to be slightly blunted, in line with DPD participants' reported experience of deaffectualization. However, given the reported severity of deaffectualization in the DPD population, the impact of emotion on cognitive abilities, or lack thereof, appears to be more limited than expected. One potential explanation may be that while DPD participants struggle with the affective experiencing of emotion, there may be a cognitive recognition of the emotional nature of the information, and hence, perceptual resources were prioritised towards those stimuli. As such, the adaptive emotional impact on cognitive abilities remain preserved.

Alexithymia, emotional recognition, and subjective experience of emotions

Alexithymia has emerged as a significant factor in DPD, as higher levels of alexithymia, as measured on the TAS-20 were significantly discriminatory of a DPD diagnosis as compared to healthy controls and participants with PTSD (Lemche et al., 2013a; Simeon et al., 2009). Simeon et al (2009) also highlighted that the DPD group showed particular deficits in the identification of their own feelings. Empathy, the ability to cognitively understand and predict another's mental state, as well as to affectively experience an emotion due to another's mental state (Davis, 1980a; Lawrence et al., 2004), was also reported to be significantly lower in people with DPD as compared with healthy controls (Lawrence et al., 2007).

However, recognition of emotions in others appears to be mostly intact in people with DPD, as no significant differences were found between DPD participants and healthy controls in identifying the correct emotion displayed in photographs of eyes (Lawrence et al, 2007), or of facial expressions (Montagne et al., 2007). It is worth noting, however, that Montague et al (2007) did find a post-hoc significance in DPD participants' lowered sensitivity to angry expressions, even with depressive symptoms controlled for. Sierra et al (2006) also found that DPD participants did not differ in emotional recognition of disgust in facial expressions but rated them as less intense than anxious participants or healthy controls. Similarly, DPD participants did not rate aversive scenes differently from neutral scenes and had significantly lower ratings of aversive emotions (fear/anxiety/disgust) when viewing aversive pictures compared to OCD participants and healthy controls (Phillips et al., 2001). Measured on an excerpt of the self-report Interpersonal Reactivity Index (Davis, 1980), DPD participants reported less egocentric feelings of personal distress in various situations where they are exposed to others' negative emotional states (Lawrence et al, 2007). This seems to suggest that the cognitive aspect of empathy and identifying emotional expressions in others is preserved in people with DPD, but that difficulties persist in the affective experience of emotions and labelling that within themselves. Supporting this, Simeon et al (2003) found that people with DPD had thinner 'mental boundaries' (Hartmann, 1991), meaning they were less able to distinguish cognitive and emotional categories and have difficulties differentiating thoughts and feelings. Collectively, this seems to suggest that while cognitive empathy appears preserved in people with DPD, affective empathy appears less sensitive as DPD patients generally seem to have a weaker experience of evoked emotions.

Almost paradoxically, people with DPD still go through significant distress over their feelings of numbness and unreality. They report experiencing more anxiety and anger, and experience negative affect more intensely than healthy controls, although no difference was found in positive affect intensity (Simeon et al, 2003). Similarly, Lawrence et al (2007) also confirm that DPD participants report higher levels of sadness, anger and fear, and lower levels of happiness than healthy controls despite having lower levels of physiological response to external emotional stimuli (Lawrence et al, 2007). This seems to suggest that their inner experience of emotions is not down-regulated to autonomic indicators such as heart rate or skin-conductance rates, and this impairment to interoceptive processes may then result in the physical experience of emotional numbness.

Neurophysiological response to emotional stimuli

Autonomic responses. It was initially found that DPD participants had reduced skin conductance baselines (Sierra et al., 2002). However, there were several limitations with the study, including the lack of consistent delivery of the physical auditory stimuli (clap and a loud sigh). When investigated in later studies, DPD participants were typically found to have elevated tonic electrodermal activity (Giesbrecht et al., 2010; Lemche et al., 2008). The elevated baseline skin conductance level fits with the idea that depersonalisation arises from anxiety, may be reflective of the heightened state of alertness in people with DPD (Horn et al, 2020).

Generally, people with DPD have been found to have smaller phasic autonomic responses to emotional stimuli than healthy controls, as measured by onset latency and peak amplitudes. This smaller rise in electrodermal activity may reflect a more limited emotional reaction. Giesbrecht et al (2010) found that DPD exhibited flatter skin conductance response (SCR) over time to emotional stimuli compared to healthy controls' rising pattern, and attributed it to a phasic selective inhibitor response in DPD to emotional stimuli. However, Medford et al (2016) found that this dampened autonomic effect was not specific to responses to emotional stimuli, as DPD participants also had lower SCR to neutral stimuli. Sierra et al (2002) also found that DPD participants showed no significantly differential SCR between neutral, pleasant and unpleasant stimuli, as opposed to anxious participants and healthy controls, who showed higher SCR to unpleasant stimuli. Michal et al (2013) found that SCR amplitudes depended on emotional valence and arousal for DPD participants although no such modulation was present in healthy controls. Despite rating unpleasant sounds as less unpleasant than healthy controls and normative ratings, DPD participants showed stronger electrodermal responses than health controls. It is interesting to note that none of the studies had emotionally primed participants prior to the introduction of emotional stimuli. However, given Medford's (2016) and Sierra's (2002) findings of dampened autonomic effect irrespective of the valence of emotional stimuli, it may be predicted that prior emotional priming may not produce any significant results.

Taken together, the elevated baseline of electrodermal activity in DPD participants may in turn impact on the observability of any differences in autonomic responses, and could explain why little to no differences in SCR after exposure to emotional stimuli were typically observed in the above studies.

Lawrence et al (2007) also looked at other physiological measures to evaluate DPD participants' autonomic response to emotional stimuli. They found that DPD participants had decreased speech rate after reading a happy vignette, and increased speech rate after a sad vignette

despite reduced levels of self-reported personal distress. The increased speech rate may reflect an increased level of anxiety, and the contrary self-reports of personal distress may be more indicative of a deficit in the interoceptive processing leading to the 'emotional numbing' commonly experienced in DPD. This may also be explained by the high levels of alexithymia within the DPD population, and the contrary self-reports reflect that inability to identify increased negative emotions within themselves.

Neurological responses. Functional brain imaging data suggests an activation of inhibitory response in the brains of DPD participants when exposed to emotional stimuli. Phillips et al (2001) found that the insula, implicated in the perception of disgust, was more significantly activated in OCD participants and healthy controls, but not in DPD participants. Medford et al (2016) also demonstrated an activation of the left insula in healthy controls and improved DPD participants after a drug trial, and non-activation of the left insula in DPD participants before the drug trial and non-improved DPD participants after the drug trial. Interestingly, the insula was more significantly activated in DPD as compared to healthy controls when shown neutral scenes, suggesting an elevated baseline activation for aversive emotion perception (Phillips et al, 2001).

When viewing aversive scenes, both OCD and DPD participants demonstrated a significant activation in the right prefrontal cortex, related to appraisal of emotional stimuli and the regulation of emotional experience, as opposed to healthy controls (Phillips et al, 2001). This inverse functional relationship, specifically between the left insula and right ventral prefrontal when viewing aversive scenes, suggests a greater regulation of inhibition by the right ventral frontal cortex of the normal insular response to emotional stimuli.

Lemche et al (2008) also highlighted an increased response in the dorsolateral prefrontal cortex to facial expressions in DPD participants, which is responsible for invoking inhibitory neural responses. This is in contrast with healthy controls, who exhibited anterior prefrontal cortex activations, responsible for 'release' functions instead of inhibitory responses. DPD participants also showed earlier peaks for haemodynamic responses post-stimuli, which correlates with discriminatory skin conductance levels found in the same study (Lemche et al, 2008). These findings suggest a faster perceptual processing of emotional stimuli, before an inhibitory response to suppress emotion.

Taken together, DPD participants appear to have a lower neurological sensitivity to negative emotions, particularly of disgust, as implicated by the reduced activation levels of the insula. This may be explained by the inhibition of the processing of these negative emotions that are often quickly inhibited, as reflected by the activation of the prefrontal cortex. This may tie in with DPD patients' inability to down-regulate their emotions to autonomic indicators. The inhibitory response following

the processing of emotion may lead to the paradoxical experience of being aware of the appropriate emotional response, but is numb to that emotion on an autonomic level. It is unclear if this inhibitory response is indicative of inherent neurobiological differences within the DPD population, or if this is an entrenched learned response to overwhelming aversive emotion due to childhood experiences of emotional maltreatment common in DPD (Simeon et al., 2001). However, abreaction, a psychodynamic intervention to emotionally relive traumatic events and release suppressed emotion, has shown promising effects in reducing symptoms of DPD (Sierra, 2009), suggesting that this inhibitory response may be learnt and potentially reversible.

Limitations and Future Research

One of the main limitations of this review is the small number of papers included in the study, despite the broad scope of the review. This restricts the generalisability of findings, and also provided an even smaller pool of studies to substantiate sub-themes. However, this is reflective of how under-researched this population is despite having comparable prevalence rates with other more commonly researched disorders such as schizophrenia (Baker et al., 2003).

Besides the small number of papers included in this review, it is also noted that generally across all papers included in this review, small sample size is a common limitation for studies investigating DPD due to the relatively rare diagnosis of the disorder. While this review intentionally only included papers whose participants have a diagnosis of DPD, many studies investigating depersonalisation may not actually recruit from the DPD population, and instead, recruit from a non-clinical population to potentially increase sample size and power (Dewe et al., 2018; Quaedflieg et al., 2013; Röder et al., 2007; Tibubos et al., 2018). DP and non-DP groups are usually then distinguished based on high and low scores on DP- or dissociation-specific outcome measures such as the Cambridge Depersonalisation Scale (Sierra & Berrios, 2000) or the Dissociative Experiences Scale (E. M. Bernstein & Putnam, 1986).

Given the subjective nature of emotion induction (for example, one person may find cues of a snake to elicit feelings of fear and anxiety, while another may not have that expected response), it was interesting to note that no studies considered the use of personalised emotional tasks that tap more specifically into an individual's specific difficulties to elicit more accurate emotional responses. This may be due to logistical difficulties for researchers to gather background information on individual participants and adapting emotional stimuli accordingly. Some studies utilised non-standardised tools such as an emotive story or diary extract to induce emotional fluctuation (Giesvrecht et al, 2010; Lawrence et al, 2007), and may check for mood induction via self-report ratings or be corroborated by neurophysiological indicators. However, some studies did not actively check for mood induction, so

as to target underlying emotional perception as opposed to emotional identification (Phillips et al, 2001). Many of these studies utilised standardised testing materials to evoke emotional fluctuation, such as the International Affective Picture System (IAPS; Lang & Bradley, 1999) or International Affective Digital Sounds (IADS; Bradley & Lang, 2007), which had been normed and validated to produce specific emotional responses in users. While personalisation of stimuli may produce more accurate mood induction, this standardisation of stimuli exposure allowed for better comparison of outcomes between subjects. Group comparisons may also mitigate individual differences in atypical emotional responses to stimuli. although small sample sizes in DPD studies, as mentioned above, may result in less robust mitigation. The lack of consistency in stimuli use across all studies looking at affective processes also meant that it is difficult to conduct any meaningful quantitative analyses in this systematic review. There was also no consistent use of outcome measures or neuropsychological tests used to measure cognitive and/or affective abilities.

One noticeable gap within the included literature is the distinct lack of discussion around diversity. All but one paper (Simeon et al, 2003) described the ethnicity and cultural background of their participants, with a large majority of participants identifying as being from a White background. It is assumed that the make-up of participants of other included studies are of similar proportions, or given the small sample size typical of this population, entirely made up of participants identifying as being from a White background. It was found that people identifying from highly individualistic cultures were more likely to experience depersonalisation during panic attacks (Sierra-Siebert & David, 2007), and that Columbian psychiatric inpatients had a significantly lower prevalence of depersonalisation as compared to British or Spanish inpatients (Sierra et al., 2006). It is interesting to note that most of the included studies take place in either the United States or United Kingdom, where the population is of a White majority, and individualistic culture is prevalent. Given the impact of culture on depersonalisation, the results of this review and the included studies may not be as generalisable to participants from less individualistic and non-White backgrounds. More research should be conducted on how DPD may present in different cultures, particularly more collectivist cultures, and how culture and depersonalisation may impact on their cognitive and affective abilities.

It is clear from this review that compared to other mental health disorders, DPD is particularly under-researched, and more research in this population, particularly on the cognitive aspects of DPD, should be conducted to better understand the underlying mechanisms of this disorder. In particular, further research may be helpful in drawing out the specific factors impacting on the cognitive capacity of people with DPD, and how excessive internal self-monitoring of DP symptoms may contribute to the reduced attentional capacity. Additionally, seeing how limited allocation of perceptual resources to other aspects of experience outside of DP symptomology may influence the authenticity of that

experience, further research into the conscious reallocation of attention through the use of attention training, task concentration training and mindfulness techniques may be helpful as potential interventions. Given the high levels of alexithymia, emotional literacy courses may also be useful for people with DPD, particularly around self-identification of internal affective experiences.

Conclusion

In conclusion, people with DPD appear to have normal levels of cognitive abilities, although slight but distinct differences in memory, attention and visuospatial abilities corroborate subjective complaints. However, it is unclear if these differences are indicative of actual neuropsychological deficits, or if they could be better explained by a reduced working memory and attentional capacity, leading to limited perceptual resources allocated for other aspects of experience. Established effects of emotion on cognition such as emotionally-enhanced memory and emotionally-biased reasoning have also largely remained intact. This may be due to the preservation of cognitive aspects of affective processes like empathy and emotional recognition despite high levels of alexithymia within the DPD population. Furthermore, the affective profile of individuals with DPD appears to be characterised by a neural inhibitory mechanism due to the activation of the prefrontal cortex after the processing of aversion emotions from the insula region. This suppresses the subjective experience of emotion and autonomic markers of emotion. As such, people with DPD struggle with interoceptive identification and affective experiencing of emotions. Further research into the underlying mechanisms and potential interventions is needed.

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Appendix

Appendix A: NIH Quality Assessment of Case-Controlled Studies

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated and appropriate?			
2. Was the study population clearly specified and defined?			
3. Did the authors include a sample size justification?			
4. Were controls selected or recruited from the same or similar population that gave rise to the cases (including the same timeframe)?			
5. Were the definitions, inclusion and exclusion criteria, algorithms or processes used to identify or select cases and controls valid, reliable, and implemented consistently across all study participants?			
6. Were the cases clearly defined and differentiated from controls?			

Criteria	Yes	No	Other (CD, NR, NA)*
7. If less than 100 percent of eligible cases and/or controls were selected for the study, were the cases and/or controls randomly selected from those eligible?			
8. Was there use of concurrent controls?			
9. Were the investigators able to confirm that the exposure/risk occurred prior to the development of the condition or event that defined a participant as a case?			
10. Were the measures of exposure/risk clearly defined, valid, reliable, and implemented consistently (including the same time period) across all study participants?			
11. Were the assessors of exposure/risk blinded to the case or control status of participants?			
12. Were key potential confounding variables measured and adjusted statistically in the analyses? If matching was used, did the investigators account for matching during study analysis?			

*CD, cannot determine; NA, not applicable; NR, not reported

From <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools>

Chapter 2

Empirical Research Project:

Exploring the subjective experiences of
Depersonalisation Disorder, beliefs and
attributions of the disorder and treatment

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Abstract

Background:

Depersonalisation disorder (DPD) is characterised by chronic and continuous feelings of detachment from the self. Despite being described and documented since the early 19th century (Griesinger, 1845), DPD continues to not be well-understood by both clinicians and researchers. DPD has been associated with childhood emotional trauma (Simeon et al, 2001), but many people with DPD also report a lack of traumatic history (Lee et al, 2012). Given that subjective experiences of childhood maltreatment were found to be more predictive of future psychopathology than objective accounts (Danese & Widom, 2020), our aim was to inductively explore the subjective experiences of people with DPD, and how differences in their experiences and journey may impact on their beliefs and attitudes towards the disorder and treatment.

Methods:

18 participants with a diagnosis of DPD were recruited from a national specialist clinic targeting DPD. We conducted semi-structured interviews that typically lasted 1-1.5h, and covered topics such as participant: subjective experience of depersonalisation symptoms; understanding of what depersonalisation is and how they came to experience it; childhood experiences and any experimentation with substances; and their journey to, experiences of and beliefs about treatment. The interviews were then transcribed, coded and analysed using constructivist grounded theory methodology.

Findings:

It was found that the interaction between participants' identification with emotionally harmful experiences and their perceived childhood environments could be into 4 broad groups: childhood difficulties (CD), stressful life change/event (St), substance use (SU) and no known cause or factor (NC). These differing attributions accounted for variation in perception of childhood experiences, perceptions about depersonalisation, and goals for therapy. Many participants also reported a pattern of emotional repression since childhood and viewed their anxious and reflective personality type as a predisposing vulnerability for DPD. However, regardless of their identification with childhood emotional difficulties or attributions for the onset of their disorder, many participants also described similar experiences and struggles with DP symptomology. They also reported common difficulties articulating their struggles and navigating the mental health system during their journey toward support, and shared initial beliefs about being 'cured' in treatment.

Conclusions:

From the findings, improving detection of DPD by providing training for GPs and encouraging clinicians to proactively enquire about DP symptoms were recommended. More accessible referral pathways, and more flexible delivery of treatment were also identified to be helpful. Further research in the potential interventions, identification and understanding of DPD is needed.

Introduction

Despite a long history of clinical recognition and description (Brauer et al., 1970), depersonalisation (DP) and Depersonalisation Disorder (DPD) continue to be poorly understood by researchers and clinicians alike, often being misdiagnosed or under-recognised (Sierra, 2009). DP is the experiencing of feelings of unreality and detachment from oneself, usually resulting in emotional numbing and perceptual disturbances amongst other symptoms. It is often accompanied by derealisation (DR), in which the sense of detachment and unreality is related to the external environment. Both DP and DR symptoms are relatively common even in the general population, as lifetime prevalence rates are estimated to be between 26-74% (Hunter et al., 2004). DPD, also known as Depersonalisation and Derealisation Disorder (DPDR), is the chronic and continuous suffering of depersonalisation, and prevalence rates of clinically significant levels of DP/DR were found to be between 1-2% (Hunter et al., 2004). People suffering from DP are not considered delusional, as most appear to remain aware that their experiences are subjective and not objective reality.

There is a longstanding debate about the classification of DPD (Sierra, 2009). Many studies have investigated DP as a syndrome in its own right or alongside other dissociative features (Černis et al., 2020; Lee et al., 2012). Whilst it is most prominently found in patients with panic disorder, it also a common occurrence in psychosis, post-traumatic stress disorder (PTSD), depression and anxiety (Mendoza et al., 2011). While DPD was only recently re-categorised as a dissociative disorder in the 11TH edition of the International Classification of Diseases (ICD-11; World Health Organisation, 2019), DPD has long been filed amongst other dissociative disorders in the various editions of Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2013). DPD appears to differ from other dissociative disorders, such as dissociative fugue, dissociative amnesia or dissociative identity disorder, in that it has not been found to be related to distinct, severe types of traumas that commonly precipitate other dissociative disorders (Simeon & Abugiel, 2006; Simeon & Hamilton, 2008). Baker and her research team (2003) found a relatively low level (14%) of childhood physical and sexual trauma reported amongst a sample of 204 participants with a diagnosis of DPD. Instead, childhood interpersonal trauma, particularly emotional abuse, was found to be predictive of DPD (Simeon et al., 2001). However, as studies often have differing definitions of highly aversive or traumatic events (Lynn et al, 2019), emotional maltreatment is less likely to be recognised or reported compared to physical and sexual abuse (Gama et al., 2021). Simeon and her team (2001) also highlighted that given the subjectivity and ubiquitous nature of emotional injury, emotional abuse and/or maltreatment may be difficult to quantify and as such, may potentially contribute to a pattern of under-reporting. Nevertheless, this apparent difference in aetiology has led to some questioning DP's position within dissociative disorders, as increasing evidence seems to point toward DPD's link

with anxiety spectrum disorders (Lee et al., 2012). However, while diagnostic manuals tend to box disorders into neat categories, mental health disorders are rarely so distinctly separate in real life. As such, instead of categorising DPD as a dissociative or anxiety disorder, it may be more helpful to understand DPD as both. Depersonalisation evidently appears to be driven and maintained by anxiety, hence closely follows the CBT model of anxiety and avoidance (Hunter et al, 2003). However, it is also more complex than simple anxiety, and a trauma-informed approach is imperative as the development of chronic depersonalisation appears closely linked to emotional childhood difficulties that is signature of dissociative disorders (Simeon et al, 2001).

Two different models of depersonalisation sought to understand the relationship between depersonalisation and trauma. Sierra and Berrios (1998) proposed the adaptive function of depersonalisation to retain vigilant alertness in the face of potentially immobilising anxiety during life-threatening situations where the individual has little to no control. This is supported by the prevalence of survivors reporting feelings of depersonalisation during traumatic events, such as a plane crash, natural disasters or being taken hostage (Cardena & Spiegel, 1993; Hillman, 1981; Sloan, 1988). On the other hand, it has also been suggested that depersonalisation does not have any particular adaptive protective function, but is instead a symptom of trauma. Supporters of this alternative explanation point to the way in which the pattern of acute depersonalisation and derealisation during traumatic events predicts ensuing psychopathology (Taal & Faber, 1997). Perhaps a more balanced view may be a combination of both explanations: while initially protective, chronic depersonalisation becomes a maladaptive defence mechanism against overwhelming emotions and/or anxiety, leading to the shutting down of emotions, affect and/or body (Sedman G, 1970; Sierra & Berrios, 1998) and in turn, contributes to further psychopathology as perpetuated by cognitive avoidance. As people negatively appraise feelings of depersonalisation and make catastrophic interpretations of these feelings, this may inadvertently lead to feeling more anxiety and negative emotion about their depersonalisation, leading to another depersonalised 'shutdown' response to these overwhelming emotions (Hunter et al, 2003). As such, the cycle of depersonalisation and anxiety can become maintained and chronic (Hunter et al, 2003). This model of understanding depersonalisation is strikingly similar to Clark's (1986) cognitive behavioural model of panic, advancing DPD's relationship with anxiety disorders. Depersonalisation is also frequently a co-occurring symptom of panic disorder, with prevalence rates ranging from 7.8 to 82.6% (Hunter et al., 2004).

Outside trauma, DP has also been found to be commonly attributed by patients to substance misuse, and these feelings of anxiety and depersonalisation may sometimes seem to be particularly exacerbated in users of cannabis (Medford et al., 2003; Simeon, Kozin, et al., 2009). However, it was found that differences between substance-users and non-substance users in self-reported anxiety and

sensory disturbances disappeared after age- and sex-matching (Medford et al., 2003). Both drug-induced (D) and non-drug-induced (ND) DP groups were found to have similar illness course, impairment, suicidality, and limited treatment response, although the D group had significantly better improvement rates than ND group (Simeon, Kozin, et al., 2009). Interestingly, all participants in Medford and team's (2003) study attributed onset of DP to their drug use, and that their drug experience was "disturbing and frightening". This seems to further support the theory that negative interpretations of physical and psychological symptoms may set up the maintenance cycle of anxiety in DPD.

The existing body of literature fails to identify distinct and generalisable cause of onset, with unclear aetiological factors such as childhood emotional trauma, substance misuse and anxiety potentially contributing to DPD (Baker et al., 2003; Medford et al., 2003; Simeon et al., 2001). The variance in the psychiatric history, comorbidities, and therapeutic trajectories of DPD patients could be indicative of potential subgroups within DPD (Baker et al., 2003; Simeon, Kozin, et al., 2009). For example, from a more dissociative angle (Janet, 1903, 1928), DP may be a learned response in patients with a childhood history of emotional abuse as a maladaptive coping mechanism to overwhelming emotional responses and interpersonal difficulties. Contrastingly, illicit drug use may lead to negative experiences of DP and panic attacks, which could be maintained by anticipatory anxiety and excessive self-monitoring behaviours (Hunter et al, 2003) that are more in line with the theoretical model for panic disorder (Clark, 1986). This varied development of chronic DP may have differing implications for treatment methods, as cognitions and beliefs of DP may differ. As such, different approaches in therapy may be more effective for conditions with different aetiological factors, such as drug-induced DP vs emotional trauma-induced DP. Despite Simeon and her team (2009) finding that drug-initiated DP participants improved more over time than non-drug-initiated DP participants, both groups reported limited self-reported effectiveness of psychotherapy or pharmacotherapy. While the specific nature of the therapy received was not known, it was acknowledged that it was unlikely that the participants received specialised treatments to target DPD, affect avoidance or alexithymia, and as such, the limited effectiveness of treatments may be more related to the non-targeted nature of the interventions.

In trying to better understand the disorder, there have been numerous quantitative studies conducted investigating the epidemiology, aetiology, and comorbidity rates of DPD (Baker et al., 2003). Many of these studies employed the use of structured psychiatric interviews, for example, the Present State Examination (Wing, 1980), in their data collection process, but analysed the data using reductive quantitative methodologies. Baker and her team (2003) conducted an interview survey of the course, onset, duration, attributions, psychiatric and family history in 204 cases of DPD to potentially identify

any clinical subtypes based on specific aetiological factors. While there was no evidence to suggest clinical subtypes, Baker et al (2003) found that earlier onset of DPD generally reported more severe symptomology, although DPD patients overall tends to run a chronic and unremitting course. However, Baker et al (2003) concluded that more research into the aetiology and treatment of DPD was needed. There are few qualitative studies that have sought to understand the disorder from the sufferer's perspective or investigated how individual's subjective experiences and journey to support might influence their cognitions and beliefs about the disorder and treatment. Given that subjective experiences of childhood maltreatment have been found to be more predictive of future psychopathology than objective reports of childhood maltreatment (Danese & Widom, 2020), the importance of looking into the subjective experience of people with DPD is especially pertinent.

Yeh (2016) looked at a case study of a man diagnosed with DPD in Taiwan, and explored the transformation of his problem throughout therapy using narrative analysis, as the focus of therapy shifted from symptoms of DP to problems in interpersonal relationships, and anxiety dipped. Tanaka (2018) investigates the experience of disembodiment and its impact on the sense of self through a phenomenological lens. Černis, Freeman & Ehlers' (2020) investigated the experience and impact of dissociation in the context of non-affective psychosis using semi-structured interviews and an inductive Thematic Analysis approach. They found that participants frequently felt that descriptions of their DP experience were misunderstood and overlooked by clinicians, and that their DP may be developed and maintained by stress, fatigue, and excessive internal focus. More recently, Ciaunica and her team (2022) examined the phenomenology of depersonalisation disorder using the Active Inference framework, a computational model for understanding neurocognitive and behavioural processes using Bayesian theory. They proposed that the 'aberrant self' in which agentic control over perception and action feels outside of the self's control, is underpinned by deficits in somatosensory attenuation and resulting abnormal perceptions.

The current study aims to address the lack of qualitative research investigating the subjective experience of DPD and the unclear aetiological picture of DPD. Additionally, given the subjective nature in how one interprets and understands emotionally adverse events, we felt it was vital to inductively explore how differences in subjective experiences of childhood and attributions may influence their beliefs and attitudes towards the disorder and treatment. To our knowledge, this is the first study to inductively investigate and understand potential differences within the DPD population from their perspective and subjective experiences.

Methods

Aims

The aim of this study was to understand how the subjective experiences and attributions of people with Depersonalisation Disorder influence their beliefs and attitudes towards the disorder and treatment.

Design

Grounded Theory (GT) was adopted as a methodology based on the constructivist approach of Charmaz (2006, 2014). Constructivism as an epistemological philosophy postulates that knowledge is actively constructed by learners through experience and discourse, as opposed to being passively acquired and understood (Piaget, 1971). Charmaz (2014) proposes the idea of theory generation, and grounded theory methods being used flexibly in order to consider the role of the researcher, and how theories are developed within the context of social and power relationships. The interpretive nature of Charmaz's approach (2014) allows for the role of the student researcher, taking their personal and professional experience into account, as well as the existing knowledge informing the field of enquiry. The theory that results from this study is a 'co-constructed' theory between the researchers and the participants. By following a constructivist approach, we sought to explore the subjective sense-making of people with DPD during the journey of experiencing DPD, and the contextual aspects that informs their beliefs and attitudes towards the disorder and treatment.

Constructivist GT methodology was chosen over other qualitative constructivist approaches in order to produce a theoretical model which captures and explains the differing sense-making and attributions of DPD. Due to time constraints on the research project, the research process was not as iterative as a GT study ideally should be, as much of the formal data analyses took place after data collection was completed. As such, reflexive thematic analysis was briefly considered as an alternative methodology to continue analysing the data collected in a constructivist manner. However, it can be argued that all efforts were made to continue data collection and analyses in an iterative manner, as informal data analyses and reflections (as captured in memos) from initial interviews informed changes in the interview guide for subsequent interviews with participants. As such, a decision was made after much discussion, to continue the study with constructivist GT methodology, while acknowledging the context and limitations of the process.

Setting and participants

This study was conducted at the Institute of Psychiatry, Psychology and Neuroscience (IOPPN), in partnership with the Depersonalisation Disorder Service (DPDS) within the Centre for Anxiety

Disorders and Trauma (CADAT). The Depersonalisation Disorder Service is a national specialist clinic, with a strong focus on delivering evidence-based psychological therapy such as Cognitive Behavioural Therapy (CBT).

Participants were recruited from the DPDS within CADAT, where service-users are diagnosed with DPD. Among the list of current and previous service-users of the DPD Service who consented to be contacted for research purposes, participants were screened for any active risk issues as an exclusion criterion, and clinicians were consulted during this process of determining risk suitability. Researchers emailed 33 prospective participants who had previously consented to be contacted for research purposes, and 18 participants (7 females, 11 males; see Table 1) were eventually recruited and interviewed. The mean age of participants was 41 years, and the majority of participants (n=16) identified as White British, while only 2 participants identified as a different ethnicity (one= White Other, one= Chinese). Of the 18 participants, 3 were currently in treatment at the point of interview, 3 were awaiting treatment at the point of interview, and 12 were already discharged from the service.

Table 1: Table showing demographic information of participants, and their clinic status

Participant ID	Gender	Age	Ethnicity	Clinic Status
101-02	M	68	White British	In treatment
102-03	F	37	White British	In treatment
103-12	F	31	Chinese	In treatment
104-13	M	33	White British	Awaiting treatment
105-14	M	60	White British	Awaiting treatment
106-15	M	28	White British	Awaiting treatment
107-16	M	42	White British	Discharged
108-17	F	57	White British	Discharged
109-18	F	26	White British	Discharged
110-19	M	28	White British	Discharged
111-20	F	67	White British	Discharged
112-21	M	23	White British	Discharged
113-22	F	27	White British	Discharged
114-27	M	35	White British	Discharged
115-29	M	29	White British	Discharged
116-31	M	44	White British	Discharged
117-32	F	42	White Other	Discharged
118-33	M	61	White British	Discharged

Data Collection

After ethical approval was obtained, the researcher advertised to current (n=16) and past (n=18) service-users of the Depersonalisation Disorder clinic via email for recruitment, and a total of 18 participants were recruited and interviewed. 16 participants were interviewed virtually over Microsoft Teams, while 2 participants were interviewed in person at the Centre for Anxiety Disorders and Trauma. All participants consented to having their interviews recorded and transcribed for the purposes of the study.

Interviews were semi-structured and lasted between 60 - 90 minutes. An initial interview guide, developed with service-user feedback (see Appendix A), was used to loosely manage the structure of the interview. A brief overview of interview topics includes: their subjective experience of depersonalisation symptoms; their own understanding of what depersonalisation is and how they came to experience it; their childhood experiences and any experimentation with substances; and their journey to, experiences of and beliefs about treatment. Over the course of the interviews, the interview guide evolved flexibly to follow the participant's concerns, and was amended and adapted after each interview to capture emerging ideas and questions. Verbatim transcription of interviews was conducted for analysis, and this was split between the lead author (n=8) and an external transcription company (n=8).

Ethical considerations

This research study was granted ethics approval from Harrow Research Ethics Committee of the Health Research Authorities (Ethics number: 21/LO/0573). The authors did not receive any form of funding for this study from any external organisation.

Data analysis and theoretical sampling

As per constructivist grounded theory methodology, the qualitative data was simultaneously collected and analysed. Due to delays in external transcription, the bulk of formal data analyses took place following the completion of data collection, but informal analyses continued to take place to further iteratively inform changes to the interview guide (see Appendix B). Checking of transcripts and transcription of interviews by the lead author also aided in the familiarisation of and immersion into the data.

The data underwent initial line-by-line coding to categorise and fracture the data, so as to allow for comparison of incidents with the constant comparison method used to search for similarities and differences in events. Following that, the data then underwent further focused coding, allowing

the transformation of basic codes of data into abstract concepts by reviewing, collapsing and refining categories. This inductive process eventually resulted in more developed categories, and eventually, the core category of the identification with childhood emotional harm emerged. Throughout, the constant comparison of data and reassessing of the meaning of the data took place throughout this process. Finally, storyline technique (Strauss & Corbin, 1998) and theoretical coding were used to integrate abstract concepts into a comprehensive and developed theory.

In keeping with constructivist grounded theory, memo-writing to record the researcher's thoughts and reflections was used to inform and guide the analyses. Memos also reflect the thought process behind changes in codes or themes, providing additional rigour to the analytic process.

Qualitative data were imported into NVivo 12, a qualitative data management tool to support coding and analyses.

Rigour, reflexivity, and validity

To enhance and demonstrate the rigour of a grounded theory, Charmaz (2006) proposes that researchers keep in mind the criteria of credibility, originality, resonance and usefulness to judge the quality of their analysis and final theory.

Credibility was established as the qualitative data collected was sufficient to support the theoretical explanations, and theoretical saturation was reached after interviewing 18 participants, as properties and dimensions of the emerged themes were confidently crystallised. The systematic application of the constant comparison methods also ensured observations and categories produced were grounded in the data. Memo-writing helped with the reflexive process by allowing the researcher space to reflect on her own positionality and relationship to the data. During the interviews, the student researcher frequently paraphrased and summarised participants' responses to ensure accurate understanding of the participants' experience. The analyses were mainly conducted by the student researcher, but the emerging codes and themes were regularly discussed with her team of supervisors, consisting of clinicians and a non-clinical experienced qualitative researcher. This allowed for outsider perspectives, as the non-clinical research supervisor also partially took part in the initial coding process to facilitate reflexivity and encourage openness to alternative meanings and interpretations.

This study also met the criterion of originality by choosing to investigate participants' subjective experiences, an area often overlooked in a disorder that is characterised by the inner experience of the sufferer. The combination of credibility and originality also increases resonance and usefulness of the study. As the theory generated from this study aims to provide a working model for

clinicians to better understand their clients and their journeys, while also providing a common experience for people with DPD to relate to, given how alone many of them felt on their journey to support.

Positionality

Given that the meaning construction in a constructivist grounded theory methodology is influenced by both participants and the researcher, it is important to share how my position as the researcher may influence the meaning-making process. I am a final-year trainee clinical psychologist from a middle-class Asian Chinese background, working in partnership with CADAT. This gives me insider awareness of how the mental health system and the DPD Service operates, as well as a scientific understanding of DPD from conducting background reading. After moving to and living in the United Kingdom for close to 8 years, I am also in a unique position of being familiar with modern British society, culture and way of life, while retaining an outsider perspective on these social processes and their history. This is especially important in terms of how the meaning construction surrounding participants' childhood experiences may be shaped by this position.

Results

Participants' identification with childhood emotional difficulties within varying childhood environments appeared to account for much of the variation within the data. Participants loosely categorised as 'identifiers of childhood emotional difficulties' were more likely to recognise the role of their early life experiences in the development of DPD, whereas 'non-identifiers' tended to perceive their upbringing as non-problematic.

This identification with childhood emotional difficulties shaped how participants made sense of and attributed the onset of their disorder, which in turn further captures the variation in perception of self, childhood experiences and beliefs about treatment. Participants appeared to fall into 4 broad categories based on their attributions of DPD onset:

- a) childhood trauma, abuse and/or neglect (CD)
- b) stressful life event or change (St)
- c) substance use (SU)
- d) no known cause or attributable factor (NC)

These 4 categories were formed over the process of collapsing and categories codes and concepts in a constant comparison method. Over the process of refining these core categories, 2 core categories of identifiers vs non-identifiers and exposure to abusive vs high pressure childhood environments emerged to form the 4 attributions in a 2x2 matrix.

[Table 2](#) summarises the defining features and characteristics of people with DPD based on the above categories and participants may fall into more than one category based on their background. However, regardless of their identification with childhood emotional difficulties or attributions for the onset of their disorder, many participants also describe similar experiences and struggles with DP symptomology, a common journey with DPD toward support, and shared initial beliefs about treatment (see Figure 1).

Table 2: Features of DPD participants according to subjective attribution of onset

	Identification with emotionally harmful childhood experiences	Non-identification with emotionally harmful childhood experiences
Exposure to abusive environment	<p><u>Attribution to childhood difficulties (CD; n=8)</u></p> <ul style="list-style-type: none"> • Onset in teenagehood, but recognise DP in childhood in hindsight • DP as a protective mechanism • Physical/sexual/emotional abuse or neglect • Difficulties in school • Sense of not fitting in • Low self-esteem; deserving of difficulties • Readiness for therapy; therapy as taking time • Different types of therapies helpful in different ways • Limited time & scope during therapy not helpful • Better understanding of self 	<p><u>No identifiable cause or specific attribution (NC; n=3)</u></p> <ul style="list-style-type: none"> • No common period for onset, but recognise DP in childhood in hindsight • DP as a protective mechanism • Down-plays difficulties in school • Sense of not fitting in • Limit in time & scope in therapy not helpful • Better understanding/ acceptance of DP
High pressure environment	<p><u>Attribution to stressful life event/change (St; n=6)</u></p> <ul style="list-style-type: none"> • Onset in YA-adulthood • DP as a protective mechanism • Issues with family finances/parental relationship 	<p><u>Attribution to substance use (SU; n=5)</u></p> <ul style="list-style-type: none"> • Teenage-YA onset • Self-blame of irreversible damage • Fear of going mad • Better understanding of contributing factors • Overcome self-blame

Making sense of DPD

Attributions of onset

Fifteen participants who identified with emotionally harmful childhood experiences tended to attribute the onset of their disorder to emotionally difficult life experiences, whether that was in childhood or adulthood. Identifiers who attributed their DPD to the difficulties experienced during their childhood (CD group) usually noticed the symptoms of DP becoming more chronic and distressing in their teenage years. On the other hand, identifiers who had a late onset of DPD around their young adulthood to adulthood period tended to attribute the onset of the disorder to a stressful life event or change in their young adult to adult years (St group). As such, variation in the age of onset of DPD appeared to influence participants' attributions and how they made sense of their condition.

This was also apparent for participants who did not identify with emotionally harmful childhood experiences. Non-identifiers were more likely to externalise attributions, most frequently to the use of substances, or to not make any specific attributions for the onset of their disorder. People whose DPD was felt to be triggered by substance use (SU group) appeared to have an onset of symptoms during their teenage to young adulthood years. However, people who were unable to attribute or pinpoint the onset of DPD to a particular factor (NC group) did not appear to have a discernible pattern in terms of their age of onset.

However, it became apparent that people from both the CD and NC groups reported symptoms of depersonalisation in their childhood, which were only recognised in hindsight:

“When I look back, and it's obvious now, and I think, as I got into uni, and started noticing it... it was like a gradual realisation, I think... At least when you're quite young, you just don't really challenge them until you really try and think about it.” [104-13, NC]

Anxious and reflective personality type

Despite their various attributions, the majority of participants, both identifiers and non-identifiers, also viewed their own personality as a potential factor that made them inherently vulnerable to the development of DPD. Participants often describe themselves as anxious and introspective, and more prone to philosophical and existential reflections, suggesting that participants shared a common personality type:

“That said, I've always been an anxious person. There were a few things that happened during my childhood to make me think that I might be more anxious than other kids. I mean the fact that apparently the age of around 5, I became acutely aware of mortality and became very afraid of it, and which I still am, to be honest. I realize I'm not there yet, but I'm approaching middle age and I am noticing sometimes I wake up in the middle of the night, terrified at the fact I'm approaching middle age. So I know that I had sort of real terrors about this when I first sort of understood it as a child. So there's always been that kind of anxiety, my personality.”

[114-27, CD]

Engaging in existential philosophizing tended to bring on feelings of depersonalisation although it may not always have been viewed as a negative experience at the time, as these thoughts could also produce a sense of wonder about the world and their place in it. Another participant even described that prior to their DP symptoms becoming chronic and maintained, they could harness this ability to induce feelings of depersonalisation through existential thinking as a fun exercise.

DP as protective

Interestingly, despite their distress around their disorder, participants largely came to view their depersonalisation as a protective coping mechanism against the difficult and overwhelming experiences in their lives:

“And I think what I did, to a large extent, was I just put it all on hold. The situation was too complex for me. I couldn't handle it, and I locked a lot of it up... I just put it all in one big block and locked it away and left it there to deal with later, if I could.” [111-20, CD]

However, while most participants viewed their experiences of depersonalisation as protective, people who attributed their DPD to substance use were less likely to hold this perspective. They were also less likely to attribute their depersonalisation to childhood experiences, which was likely linked to their subjective experience of having a good and non-problematic upbringing.

Perceptions of childhood experiences

Naturally, people who attributed their DPD to childhood difficulties were more likely to report and name experiences of abuse and/or neglect growing up, and these may encompass physical or sexual abuse. However, across all 8 participants within the CD group, the emotional and psychological nature of these difficulties emerged as having the greatest subjective impact:

“Yeah. I feel that my father's narcissism sort of denying me the capacity to have a sense of self or a feeling of myself, which is still there but very buried, but my father's sort of narcissism made it very difficult for me to you have a sense of secure self instead I find myself extremely dependent upon fulfilling the criteria that he set for his acknowledgement, If you do this I will acknowledge you, If you do this I will love you.” [110-19, CD/SU]

Although the St group did not report any overt experiences of abuse or trauma in their childhood, it emerged that other difficulties, such as unstable family finances and/or a strenuous relationship between their parents, were present growing up. Participants from the St group spoke to the negative emotional impact of growing up within those environments, and how that often places a greater expectation on them to take on roles or responsibilities that were more mature for their age. Common examples often include taking on a parental role for younger siblings or learning to parent themselves. On the other hand, people who attributed the onset of DPD to substance use, or had no particular attribution for their DPD tended to perceive their upbringing as normal and unproblematic:

“Well, I think my early childhood, what I would describe as, you know, as healthy and happy as anyone's, I could probably, you know, I don't recall any difficulties.” [105-14, NC]

Looking back on their childhood experiences, however, participants from both the St and SU groups recognised growing up in a high-pressure and/or high-achieving environment. This resulted in participants feeling pressured or burdened by high expectations of themselves. Academic achievement was particularly valued within the SU group:

“So I think the whole thing with [my mother] being quite strict and I'm having this image of like, I've always got to [be] doing my best and be successful, and obviously, I worked very hard in school. And also there was a whole thing like my parents sent me to private school. So like they were they were paying for my tuition, and my mum was working really hard to allow me to go to private school. So it's like doing well and like, I don't know, I guess being successful, even though they never explicitly said that. But there was always that sort of expectation that I need to do well.” [112-21, SU]

However, childhood difficulties may not have been confined to the home as people from the CD group identified difficulties in school as well, typically being subjected to bullying. Interestingly, despite not having described their childhood as particularly difficult or traumatic, similar experiences

of and/or exposure to school bullying within the NC group also became apparent. However, participants from the NC group may not fully identify with such experiences, as they tended to minimise or downplay these difficulties in school:

“I was never quite the target of bullying, but occasionally a little bit here and there. But it was never quite so bad” [104-13, NC]

Older participants may also allude to a generational difference in school culture, as school violence were regarded as the norm:

“School in those days was a bit of a rough and tumble place is what I would say and I wasn't at the bottom of the pile, I wasn't at the top of the pile so I wouldn't say that I was, you know, I wasn't exceptional.” [105-14, NC]

These difficulties in school appeared to foster a sense of not fitting in for the people from both the CD and NC groups:

“And socially, I suppose you would say, like most school kids, you kind of just navigate your way between the different currents, you know, trying to find their place in in in some kind of hierarchy.” [105-14, NC]

Pattern of emotional repression in childhood

On reflection, the majority of participants identified a pattern of emotional repression, particularly of negative emotions, since a young age. This pattern of emotional repression may be a learned response for some participants, particularly those from the CD group, as they received invalidating and/or aversive responses when expressing emotions or vulnerabilities:

“Well, my mother certainly wasn't interested. She had this sort of catchphrase of ‘Nobody cares how you feel. Just keep it to yourself.’ But at the same time, she was a difficult person, because, on one occasion, she would encourage you to confide in her. And then the next thing you knew, it was being thrown back when she was angry about something... you were being attacked for it and despised for it.” [111-20, CD]

However, this pattern of emotional repression might not always be perceived as negative and unhealthy, and instead, be viewed as a neutral value of stoicism, depending on context. Participants noticed that this value of stoicism might have been internalised due to a British culture of maintaining a ‘stiff upper lip’ [102-03, CD] and just ‘make do’ [115-29, St], and this pattern of stoic behaviour was considered being ‘mature’ [108-17, St]. This pattern of emotional repression had been also embodied

in parental figures as well when they were growing up. In particular, men with DPD also identified this implicit societal expectation of being stoic to be especially strong for males, as if their ability to repress emotions, usually negative emotions, was directly related to their maturity and masculinity as men:

“Whereas for my dad, it’ll be “Big boys don’t cry. Grow up and be a man.”

[101-02, CD]

It appeared that this emotional repression might have been so internalised for a few participants, most commonly from the CD group, that they expressed difficulty in even identifying and regulating their emotions. They might refrain from doing so out of ‘shyness’ or ‘embarrassment’ [109-18, CD/St], indicating an underlying view that emotions were negative phenomena to be ashamed of. This appeared particularly strongly for males as expressing emotions and discussing their feelings were described to be ‘sissy’ [101-02, CD] or ‘a woman thing’ [116-31, SU], and therefore wrong or not socially acceptable for men to engage in. As such, some of our male participants spoke about growing up in an environment where they did not feel they had anyone to speak to regarding their emotions, even if they wanted to. In fact, some male participants encountered explicit discouragement to do so, as they remember being blamed or punished for emotional expression when they were young:

“My father didn’t like me crying, and I used to run up to him, give him a hug when I saw him, and he used to recoil. So I think, okay, that’s not the way to behave. And also, he got to a point whereby he actually said to my mother, ‘I don’t think I’ve got to come and see the boys this weekend or whatever. This is obviously upsetting [him]’, so I would then change my behaviour.” [118-33, NC]

While some family environments, usually from the St or SU group, were described as generally encouraging emotional expression, this pattern of emotional repression seemed to emerge more subtly, as several participants spoke of a tendency to prioritise others’ (often their parents’) needs before their own. In particular, St participants who experienced financial difficulties or issues with their parents’ relationships, recollect choosing not to share their emotional struggles due to a desire to reduce the burden on their parents:

“I think it’s more of the fact that I took upon myself, rightly or wrongly, and probably wasn’t asked to directly, but I definitely took on a lot of my parent’s stress... And I think I just wanted to ease the stress on my parents... But there’s definitely a lot of... sacrifice is a strong word on my end, but sacrificing parts of me probably, to make things a lot easier for them.” [115-29, St]

Self-criticism

Many participants from CD group appeared to internalise their early life experiences of abuse and neglect, presenting with self-hatred, as if they were deserving of their difficulties with depersonalisation. This seemed to manifest in self-sabotaging behaviour that prevented them from allowing themselves to feel better:

“As soon as I start to feel, ‘Hang on a minute. I’m okay here. I’m not terrified of my own existence.’ As soon as I was aware of that, the sort of defences started to crumble down because I couldn’t say to myself, or felt like I needed to say to myself, ‘Why should I feel okay? Why should I not feel completely fragmented?’ And so it meant that after I was 25, this sort of the experiences of depersonalisation became much more continuous or rolling. Any sort of feeling of security I got was almost very quickly undone by me.” [110-19, CD/SU]

Comparatively, participants who attributed their DPD to substance use presented with self-blame, particularly around having done irreversible damage to themselves, which was tied to fears around going mad or psychotic:

“You hear of these people that do like psychedelic drugs and then they’re never the same again. And they end up on some ward or whatever. It’s like some as a patient in some a mental health institution or whatever. And I thought I thought I was going that way.” [112-21, SU]

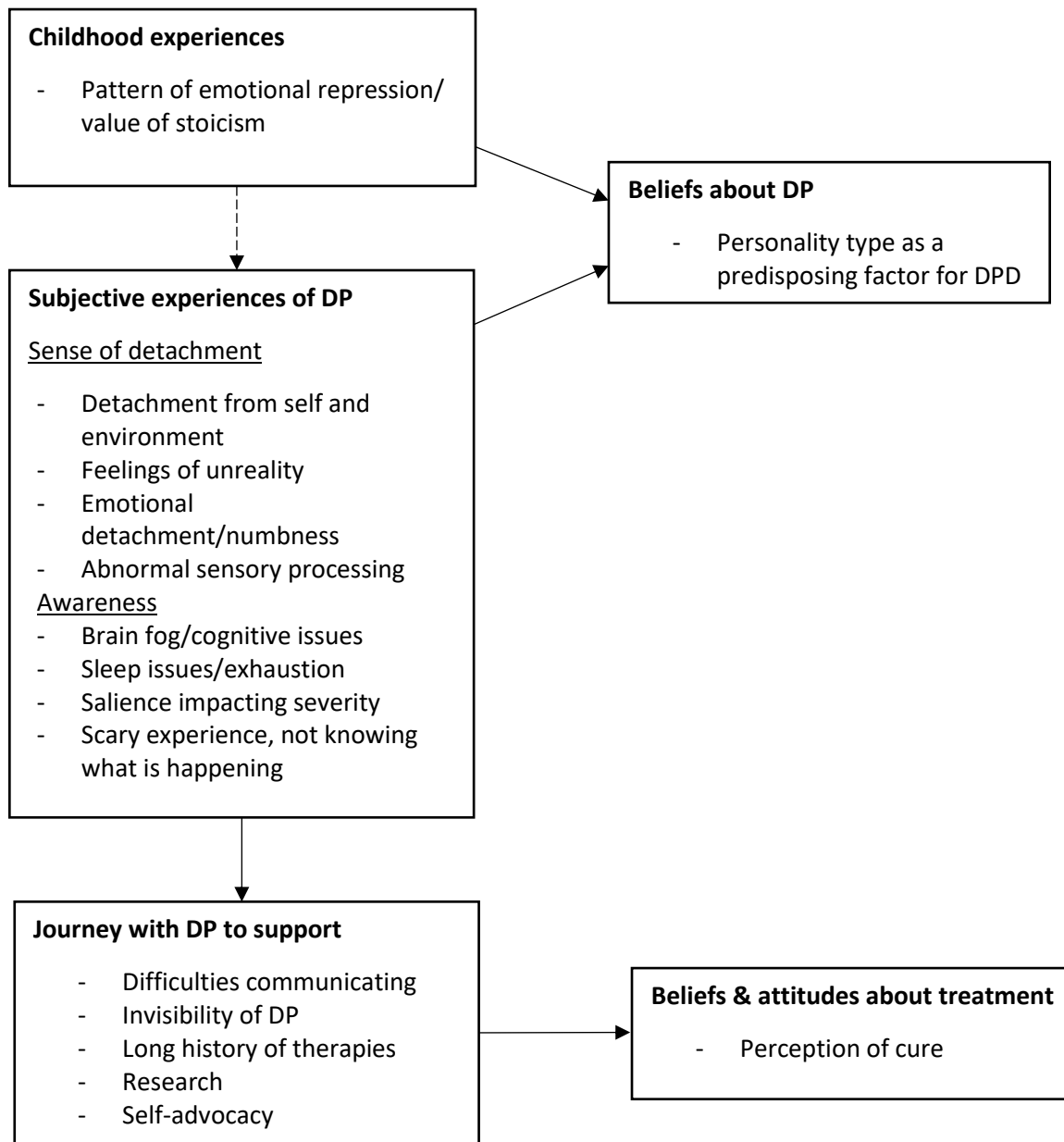
Shared experiences and journey with DPD

Sense of detachment

Regardless of how they made sense of the disorder, participants generally reported common experiences of depersonalisation such as a sense of detachment from themselves and their environment, which were in line with previously reported experiences of depersonalisation in literature. As expected, a sense of detachment or disconnect from their self, or having “*no unifying sense of self*” [104-13, NC] emerged as the most prominent core experience of DPD. This appeared related to feeling as if the conscious self was disconnected from the physical body:

“...the sensation of not seeing myself from outside my body, but almost seeing myself from inside my body, which sounds really weird, but it’s like an out of body experience from inside my body.” [102-03, St]

Figure 1: Figure showing common experiences and beliefs of participants



Other feelings of disembodiment, such as feeling as if their hands did not belong to them despite rationally being aware of this fact, also appeared as a common experience amongst participants. All the participants also heavily described feeling detached from their emotions, or emotionally numb. Often, this was presented an almost robotic experience of emotions, as participants describe rationally know which emotion they should be feeling in various contexts, but that they were not able to affectively experience the emotion inside of themselves:

“In terms of feelings, I would say it's like a complete numbness of feelings. Like I'm sort of completely indifferent to everything in my feelings. Like if I'm in a

situation where I know I should be feeling happy or feeling sad or something, that should make me feel certain feeling, I don't feel connected to that feeling like emotionally.” [112-21, SU]

This sense of detachment also extended to a detachment from behavioural actions as well. Despite feeling ‘checked out’, majority of participants described still being able to maintain functionality, as their bodies just moved on ‘auto-pilot’. However, this could be distressing to some participants, as they felt as if they lacked a sense of agency or control over actions, and that their actions were not consciously driven by themselves.

This detachment could also extend outside of the self to their environment as well. This was sometimes described as seeing the world through “*some kind of slightly unnatural filter*” [107-16, SU] or as if “*there is something in between me and the objects*” [105-14, NC]. This was most often reported in terms of abnormal sensory processing, and commonly encompassed the visual, auditory and/or tactile senses:

“I do have a full depth awareness. It's not like I can't see a car coming towards me or birds flying through the sky. But when I'm looking at it, I imagine that it's just the 2D representation that seems more realistic to what I'm looking at than a 3D. It's somehow looks as if it's a page rather than a proper image. Bit flat.” [105-14, NC]

Tactile differences, usually in the form of a delayed and/or blunted sense of touch, were also commonly linked with feelings of disembodiment as discussed above. All the above symptoms could lead to strong feelings of unreality, as participants often questioned the nature of their living experience. A small number of participants described more extreme doubts about reality when their disorder was more severe, and reported feeling as if their lives were not real, but were instead the product of a dream or imagination while their true bodies or selves existed on a different world or plane:

“You could be lying in like a [psychiatric] ward or something, and you're envisioning your life rather than that it's actually real. I could be thinking ‘this is the world’ or I could think ‘this is not real. I'm just in some sort of [psychiatric] ward and this is like a dream world’.” [116-31, SU]

These feelings of detachment and unreality can make actions and behaviours seem inconsequential, and feelings of emotional numbness also resulted in a lack of fear of consequences.

As such, some participants spoke to becoming more reckless and apathetic to potentially aversive or dangerous consequences, such as crossing the road without checking for traffic or being unperturbed by their own socially unacceptable behaviour and the effects it can have on others.

Awareness

Salience of the above-described feelings of depersonalisation appeared linked to the subjective severity of depersonalisation symptoms themselves, as the majority of participants described feelings of depersonalisation becoming more unbearable when they were more aware of these feelings. Conversely, when participants were distracted by other tasks, feelings of depersonalisation appeared more manageable:

“The symptoms, I would say, they were fairly continuous, and they are a lot less... obvious when I'm distracted. And of course, work at the time, it's... one is distracted, you know. You can read or watch TV or get absorbed in something, and other symptoms, obviously, are more much more apparent when you're not distracted.” [105-14, NC]

However, besides these feelings of detachment, participants also often reported cognitive difficulties, such as memory or attentional issues, or ‘brain fog’. This impacted on their ability to be fully aware of their day-to-day living, and participants often reported needing to put in conscious effort in taking in their environment or actions in order to be present, or to function adequately. Sleep issues and constant fatigue also emerged as a common complaint amongst participants, and this could also exacerbate participants’ ability to be fully aware of their living experience:

“Essentially, there's also an aspect of it for me, was this kind of exhaustion of... Sometimes you could physically feel the weight of that separate barrier, or let's just let's say, you were like internal of yourself, it felt like you were carrying yourself at times. And if you're really in a heightened state of it, it can feel like life is quite slow and laborious.” [115-29, St]

Participants also often expressed how frightening and scary these experiences of depersonalisation were to them, especially during the initial onset of the disorder. This fear appeared rooted in not knowing what was happening to them, and feeling as if they could no longer trust a basic fabric of reality:

“But the terror when I first started having these experiences, was... a sense that these feelings of unreality or unself or depersonalised sort of, I'm not a person, I have no self, where is myself, what is self, what is anything?” [110-19, CD/SU]

These feelings of fear often served as motivation for participants to begin the journey to seek support for these subjective experiences of depersonalisation. However, while their subjective experience of DP symptoms can be terrifying initially, most participants described eventually learning to adapt and live around their depersonalisation despite the impact DPD continued to have on their lives:

“To say it becomes normal, that is absolutely not true. You know, you kind of learn to live with it, I think.” [105-14, NC]

Difficulties with communication

However, many participants explained that starting the journey to support for depersonalisation disorder could be tricky as they often struggled to articulate these feelings of depersonalisation. This difficulty in articulating their struggles was further exacerbated by initially being completely unaware of what depersonalisation is, and the lack of language or label to define these strange experiences. Participants often relied on the use of metaphors and similes to compare their experiences of depersonalisation to more relatable examples, but caveated that these experiences could not be completely captured by language. These difficulties with articulating their feelings of depersonalisation, often further exacerbated by the lack of awareness of DPD in healthcare professionals, made it difficult for many participants' DPD to be recognised and diagnosed:

“So, I mean, I had no idea what it was called. I would describe it as feeling disconnected, and they wouldn't really know what it was. I didn't have a clue. I don't think [the healthcare professionals] had a clue.” [106-15, SU]

Difficulties with mental health system

When seeking help from doctors or other mental health professionals, many participants' difficulties with their experiences of depersonalisation were also often minimised as simply anxiety and depression, or misunderstood for symptoms of more severe psychopathology, such as psychosis. This misunderstanding of DP symptoms often resulted in participants being constantly referred to and dropped by mental health services that were not appropriate for their presentation. This might be related to the lack of awareness around the depersonalisation syndrome amongst healthcare professionals and the miscommunication between participants and service providers due to the

difficulty articulating their struggles. As such, most participants tended to have undergone many courses of therapy or mental health support, many of which were not targeted towards working with experiences of depersonalisation:

“There were quite a lot of stages before that, like when I was at school, and I saw like a counsellor at school. But that was completely pointless. I was just sort of like talking about how I was feeling, and I didn't feel like it helped at all. And then I went to a local depression and anxiety clinic, and I had some online resources to look at, but it just felt like it wasn't helping at all. It was like they were just trying to sort of treat me in the same way that they treat every other mental illness. It didn't feel like personalized at all.” [112-21, SU]

It was noted that many participants who were of an older age tended to have greater difficulties with the mental health system in their younger years, as knowledge and awareness of DPD at the time was extremely low.

Feeling alone

Participants also expressed their frustration around the invisibility of their disorder as they often still present as adequately functional:

“People wouldn't know, even those closest to me wouldn't be aware, because I'm conversing as I would normally.” [115-29, St]

Despite desperately wanting to be understood, it became apparent that most participants felt that others would never fully understand what it was like to live with DPD and empathise with the struggles. This could often result in feelings of isolation, especially since many participants had never met another person with depersonalisation. As such, feeling alone in their struggles emerged as a strong theme amongst most participants:

“It's a very lonely place, very lonely. Especially when you tell people there's things are distorted... It's a very lonely, imagine you're in a group of people, and you're the only one that is just spaced out. It's just a very lonely place.” [117-32, CD]

Self-reliance

These feelings of being alone in their struggles also usually resulted in a lonely search for answers, as a majority of participants described having to seek solutions on their own, by doing their

own research. Often, many participants point to the moment they learnt of the term 'depersonalisation' as one of great relief and validation:

"I did a bit of research online and I just remember feeling so amazing! Like, oh my gosh, everything that I'm feeling because I had no words for [it], I couldn't really describe these dream-like feelings, I just constantly described it as 'I feel weird. I can't really say why, just weird.' And then I looked at other people's experiences and more definitions and I was just so happy that I wasn't crazy... and this [was] a thing! People are selling it [sic]. People are writing it. This experience that I'm experiencing, and they're writing it and it's real and it's acknowledged somehow... I felt really understood and I felt really good." [113-22, CD]

However, this process of self-discovery and self-diagnosis also meant that the majority of participants had to self-advocate to get the support that they need for DPD:

"I kind of had to push for it myself in a weird way, because when I was living in [place in England] and I was talking to a head of a therapy place there, he said he had asked around, he said there's not anyone that can treat it in the whole southern NHS." [104-13, NC]

This long journey to support fuelled by self-reliance and self-advocacy often resulted in frustrations and participants feeling that they were provided with inadequate support from the mental health system, and that the responsibility of pushing for appropriate support was shouldered solely by themselves. This created further stress for participants, and there was a lot of frustration around how long the process to receiving the right support can take:

"The whole process was just so frustrating because I was there thinking, 'I'm not having panic attacks daily, but I'm really struggling here.' And the waiting times, and having to just work it all out yourself, and jump through hoops. I remember I had to go to my GP and say, 'I need to get a referral to this specialist depersonalization clinic.' And then before that, I had to get referred to another secondary clinic which was just for [general] mental health issues before I could get referred to the specialist clinic, and it just felt completely pointless." [112-21, SU]

Understanding therapy, depersonalisation and the self

Perception of cure

Although not usually actively conscious of this initially, it emerged that a large number of participants held a perception of being cured or 'fixed' upon their arrival at the specialist clinic for DPD:

"I think I was actually a little bit but naive going into it because I thought that 'OK, this is it! Like I'm at the special depersonalisation clinic. After this I'm going to be fixed!' Like I did have that image, which is completely like naive of me. I thought, if I just do these whatever it was, these few months of treatment, then afterwards I'll be back to normal and I'll be fixed and it'll be fine." [112-21, SU]

Naturally, given their long and tedious journey to receiving specialist support, there was a strong sense of disappointment when participants realised that this hope and expectation of being cured was not going to be realised:

"But I think within the first couple of sessions, I was very aware that I'm probably going to have this for the rest of my life and I really struggled with that with [treatment], because I found out that it wasn't really a cure, and it is still very new therapy. And I think that was a bit disheartening for me, to be honest... And then just to kind of cope with depersonalization, I was like, 'I don't want to cope with depersonalization, like I want it gone!'" [113-22, CD]

Therapy as bettering understanding

However, despite not having as much change in their symptomology as they expected, a majority of participants did find therapy to be helpful on the whole. Participants reported a qualitative change following treatment, and that they usually walked away from treatment with a shift in their perspective, which they found helpful:

"Yeah, as the same feelings [of depersonalisation] before and after [treatment]. But now I'm quickly... I'm able to quickly get them to go away because I'm more rational and thinking." [116-31, SU]

However, the specificity of this qualitative change appeared to differ from group to group, and this might be related to having differing presentations, goals and expectations of therapy. People who attributed the onset of DPD to their childhood difficulties reported being able to better understand and come to terms with themselves and their childhood experiences following therapy:

“But it's almost like even if I understood what I was going through, it doesn't matter until you can like experientially allow yourself to sort of feel what you're going through, rather than just describe it from a distance through intellectual abstraction. But being allowed to forgive myself for what I was experiencing is really, really big thing.” [110-19, CD/SU]

People who attributed their DPD to substance use reported a change in attribution following therapy, as they gained a better understanding of potential contributing factors to DPD, as well as a more realistic understanding of the sustained effects of substances. Following therapy, all the participants from the SU were found to no longer attribute the onset of their disorder to substance use and had a better understanding of potential emotional impact of their childhood environments. Feelings of self-blame and guilt that were a key feature of the people who attributed the onset of DPD to substance use were also reportedly reduced following therapy:

“During my therapy, we decided with my therapist that there would be a good idea to tell [my mother about my drug use] as my treatment for my perception of depersonalisation, and I did tell her and it felt really good obviously... it was like a big relief, because she took it really well and it meant that I could sort of stop beating myself up so much about it, and not worrying so much.” [112-21, SU]

On the other hand, people who had no subjective attribution for DPD felt that they had a better understanding and acceptance of the experience of depersonalisation itself:

“Yeah, there's like a lot of acceptance with it, like knowing there's not like a cure, like take this pill and it's gone kind of thing. Knowing more about it made a lot easier to live with, I guess... When it's this big, scary, unknown demon thing that you haven't got a clue what it is, or why it's happening, what's going on, it's very scary, but understanding it helps a lot.” [104-13, NC]

Therapy as taking time and effort

The concept of therapy, or any form of change, as taking time and effort before benefits may be visible was also particularly resonant within the CD group:

“But what I do find is that the problem... the benefits are not immediate. It takes weeks, months and that can sometimes... really, really derail you in identifying that benefit. Entering a better period, it happens by accident because often, you'll go for a week trying to have a good lifestyle, try and do all the right

things and you can still feel worse at the end of it. And in fact, after the second or third week in, that gets really grating. And it takes real long term lifestyle changes for it to really help. And that's part of the real barrier to actually finding solutions, is that in the real world, you get pretty motivated because you think you're doing the right thing, and after a few weeks, you get exhausted.” [114-27, CD]

Given their history of childhood trauma, people who attributed the onset of DPD to their childhood difficulties felt that the limited time and scope in CBT for DPD was not helpful, and that they would have preferred more time to build trust and open up:

“My anxieties in my psychology feels like a tangled knot. I don't know where to begin with it, and I don't... I'm not sure you can really resolve it in the amount of sessions we had.” [114-27, CD]

Interestingly people from the NC group, who despite not identifying with the extent of childhood difficulties as the CD group but shared similar difficulties in school and a felt sense of not fitting in, also shared the same sentiments about CBT for DPD.

Preparation for therapy

People who attributed the onset of DPD to their childhood difficulties valued the idea of being ready for therapy. This might be related to having had a long history of psychotherapy, across various disciplines, and how those previous therapeutic experiences prepared them to work specifically on their experiences of depersonalisation:

“I don't think there was a type of therapy, or a type of care, that would have got me here faster. I had to be ready. Like, if I had done the kind of therapy I'm doing now three years ago, I would have just refused. I would have said, ‘No, I'm bored of this. It's made up. No, no.’ Because I just didn't want to feel what I would need to feel.” [110-19, CD/SU]

In particular, the CD group felt that the various types of psychotherapy that they had engaged with in their journey with DP were each helpful in their own ways:

“I probably wouldn't have got what I did out of the CBT if I hadn't done the previous work. I certainly wish that CBT had been available when I was in my twenties, but I would have had so much other baggage at that time, so much I wasn't aware of, that I doubt, I don't know what the effect would have been.” [111-20, CD]

“Thing is about CBT, it's very practical. Now, I could talk about my fantasies with [psychotherapist] and we can talk about my father... but sometimes you can have a generalized psychotherapy. It's not focused... It doesn't mean that that was wrong, and it was a really good experience for me. I learned a lot and I won't be the person I am now if I'd just done CBT, then I'll mostly still be a bit of a racist and a bit of a whatever... I think psychotherapy has its place and I think that CBT is a different animal, different spanner.” [101-02, CD]

Discussion

In summary, this study constructs a theory that the subjective attributions of people with DPD were largely influenced by their differing childhood environments, and their subjective identification with emotional harm within that environment. This interaction between participants' identification with emotionally harmful experiences and their perceived childhood environments shaped participants' understanding and attributions of their disorder into 4 broad groups: childhood difficulties (CD), stressful life change/event (St), substance use (SU) and no known cause or factor (NC).

It emerged that participants tended to report growing up in seemingly abusive or high-pressure environments, although the identification with their childhood emotional difficulties influenced their perception of their upbringing as normal and/or unproblematic. Across the groups, however, a common pattern of emotional repression became apparent following analysis. This might present as a learned response to emotionally invalidating environments, prioritising others' needs before their own, or a cultural value of stoicism, especially for males. These experiences appeared to contribute to their sense-making of DPD, as the SU group was found to be least likely to view DP as a protective coping mechanism. It also emerged that an anxious, sensitive personality prone to existential reflections was felt to predispose vulnerability to DPD, as reported by most participants.

A majority of participants also reported common feelings of detachment and awareness of distress, which led them to seek support. However, they often reported shared difficulties communicating their struggles with depersonalisation, which often served as a barrier in accessing appropriate support from the mental health system. As such, a reliance on self-diagnosis and self-advocacy for appropriate support emerged as a strong theme, common in many participants' journey to support.

When entering treatment, many appeared to bring an expectation that they would be 'cured' and were disappointed upon realising that that was unlikely. However, therapy and change as taking time and effort was a concept that some participants were more appreciative of following treatment. Therapy was generally described as helpful, as effects of therapy were highlighted as gaining a better understanding of the self, the disorder, and its contributing factors. However, some participants, most often from the CD group, highlighted a sense of 'readiness' for therapy that was required before they could more effectively benefit from it. CD and NC participants also spoke to how limited time and scope in CBT was not helpful as some participants felt they needed more time and space to open up and trust.

Placing the findings in context

I will now discuss these findings with reference to the relevant literature, before critiquing the study and examining its implications.

Subjective identification with emotionally harmful childhood experiences

The findings of our study reflect and potentially explain the sizable minority of people with DPD who do not report trauma or neglect in their childhood experiences (Lee et al., 2012) despite the disorder's strong links with emotional maltreatment (Simeon et al., 2001). While participants, especially those from the NC group, might not identify with having emotionally harmful experiences in their childhood, particularly those that did not articulate any particular attribution for the onset of DPD, it was interesting that they might still report aversive environments in their childhood, especially in school. This resistance to label or identify their experiences as difficult or traumatic may be related to the downplaying of their difficulties and feeling as if what they experienced is 'not as bad'. For example, more elderly participants spoke of school violence as just 'how things were' back then. The overlap of various features of the CD and NC groups, such as similar feelings of not fitting in and needing more time in therapy to open up, also begs the question if their similarly emotionally aversive childhood environments may have triggered similar mechanisms that underpin their presentations, despite NC's non-identification with childhood emotional trauma. Gibb, Abramson and Alloy (2004) found that the source of emotional maltreatment may be a mediating factor in the development of subsequent psychopathology. While both parental and peer victimization is linked to higher levels of negative automatic thoughts, only parental victimization is shown to be significantly related to lower levels of positive thoughts about the self. This indicates that children who only experience peer victimization may potentially have stronger resilience to the effects of peer-directed emotional abuse, which may provide an explanation for some of the differences in age of onset of DPD.

Besides the NC group, people who attribute the onset of DPD to substance use also do not identify with emotionally harmful childhood experiences and tend to report having had an unproblematic upbringing. However, they may identify being brought up in a high-pressure environment with a strong emphasis on academic achievement, which may be quite strict and controlling. This may lead to individuals placing a greater value on retaining a sense of control, which may explain why DP symptoms can be particularly distressing, as they worry and fear going mad and losing control. This links back to the subjectivity of emotional trauma. Sierra (2009) noted that emotional maltreatment or neglect can often be subtle and implicit in certain life events and unintentionally inflicted. He listed examples such as parental divorce, emotionally distant parents,

being sent to boarding school at a young age, taking on adult-like roles of responsibility and being subjected to bullying at school without adequate protection from significant adults. He also noted that patients without such emotionally difficult history are usually gifted individuals or only children raised in high-achieving environments (Sierra, 2009). From a psychodynamic perspective, parents of such people were surmised to relate to their children as objects for their own narcissistic gratification, rather than as whole beings (Torch, 1987). Over time, it is proposed that such relational needs become internalised as the children build their sense of self as a performing object dependent on external sources of approval, and eventually adopt similarly high standards for themselves (Sierra, 2009). This suggests that there may be a stronger relationship between DPD and emotionally aversive childhood experiences than previously reported, providing more evidence towards the role of childhood emotional trauma in depersonalisation.

However, given that subjective reports of the severity of child maltreatment were found to be more closely linked to future psychopathology than the objective court reports of child maltreatment (Danese & Widom, 2020), it is interesting that participants who do not identify with emotional harm from their childhood experiences may go on to develop DPD in their later life. This may potentially be explained by the strong pattern of emotional repression that emerged from many participants' childhood, relating to the psychoanalytic theory of repression (Breuer & Freud, 1895). This aversion to emotional expression could similarly be negatively, neutrally or even positively viewed depending on subjective experiences of valuing stoicism or putting others' needs before their own. This pattern of emotional suppression may also explain why participants from the NC group were more likely to downplay the emotional impact of their exposure to school violence, as they may have difficulty identifying the suppressed emotions that arise from those experiences. Given that alexithymia was found to be significantly predictive of depersonalisation (Lemche et al., 2013; Simeon et al., 2009), and that many SU and NC participants report a new perspective on their childhood experiences following therapy, the emotional trauma of their childhood experiences may have been suppressed unconsciously, leading to participants failing to identify and be subjectively aware of this emotional impact. fMRI studies (Medford et al., 2016) indicate that this pattern of emotional suppression also pervades autonomic systems, as DPD participants demonstrate a dampening of autonomic arousal (eg skin conductance) to emotional stimuli, as compared to an increase in autonomic arousal levels in healthy controls. This may suggest that participants may have an especially entrenched learned response of emotional repression, even within the body. Seeing how common this pattern of emotional repression is across all participants, training to express their needs and emotions may potentially be an important area to address in treatment. Abreaction, the release of suppressed

emotion in psychodynamic therapy, usually under the influence of hypnosis or drugs, has shown to be promising in treating DPD (Sierra, 2009). There has been no recent systematic review on the efficacy of abreaction to measure its effectiveness, but imagery-based treatment techniques, such as imagery rescripting and imaginal exposure, to train emotional expression may provide similar therapeutic results. However, the ability to generate vivid mental images has been found to be reduced in DPD patients (Lambert et al., 2001), and this serves as a potential barrier for the effective use of such interventions.

Sense of self and personality

The majority of participants also strongly identify the role of personality in the development and maintenance of their disorder, often referring to an anxious, sensitive and/or introspective personality type that is prone to philosophical and existential reflections. Fantasy-proneness, as a personality trait, was found to be as predictive for dissociative disorders as childhood abuse (Pekala et al., 2006), and this construct appears related to this tendency to dwell on philosophical and existential questions. Participants may describe themselves as having ‘an unquenchable thirst because there doesn’t seem to be an answer to the question of what any of this [existentialism] is all about’ [107-16, SU], or preferring to ‘[live] in the world of books and stories’ [111-20, CD]. It may be viewed as a form of cognitive avoidance, as becoming absorbed into a fantasy world, or contemplating unanswerable existential questions can be a coping mechanism to mentally escape a difficult or stressful situation (Loi & Jamieson, 2010). Avoidance behaviour is also highly linked to higher levels of anxiety, and this was echoed by many of the participants, describing themselves as ‘always an anxious sort’. Interestingly, Niemyjska and Dąbska (2016) found that within a non-clinical sample, a decreased self-concept, as measured by fantasy-proneness and a decreased need for closure, significantly predicted feelings of depersonalisation (described as ‘delusion-like experiences’ or an ‘unusual state of mind’) in individuals with a younger age, and that identity exploration mediated the relationship between younger age and depersonalisation. This could be understood within the context of self-exploration as one comes of age, and the decline in fantasies and existential explorations as one ages, matures and solidifies a sense of self. This may then suggest that people with chronic depersonalisation and higher levels of fantasy-proneness may be stuck in a lower developmental stage, exhibiting the child-like need to develop a secure sense of self which they were not able to adequately explore due to their adverse childhood environments. This also appears related to how individuals growing up in high-achieving environments may foster a sense of self that is dependent on external sources of approval, and as such, do not have a stable internal self-identity. More research into

whether cultivating a stronger sense of self through therapeutic interventions such as values-based therapy and assertiveness training may be potentially helpful in the treatment of DPD.

Difficulties with communication & mental health system

The common experience across all participants with DPD in terms of having difficulty communicating or describing their depersonalisation, also observed first-hand in the interviews, can also be found in other populations struggling with dissociation. Given the high levels of alexithymia within the DPD population (Simeon et al, 2009; Lemche et al, 2013), difficulty in labelling emotions and internal experiences may also contribute to this struggle in articulating their feelings of unreality. Černis et al (2020) similarly found that people with non-affective psychosis report feeling unable to or struggling to describe their dissociative experiences, often relying on 'as if' statements or metaphors to capture their subjective experiences of dissociation. Corroborating our findings, Černis et al (2020) also linked this difficulty in describing their experiences to listener misunderstanding: clinicians often misinterpret these descriptions of dissociation with depression and/or anxiety, and as such, patients often feel misunderstood, and may receive inappropriate treatment. Given that the CD and NC group described a lack of recognition for their difficulties since childhood and these feelings of being misunderstood or unheard may be triggering for these particular patients.

These common findings suggest that these difficulties in describing subjective experiences and resulting miscommunication with the mental health system are not specific to DPD itself but are emblematic of a larger issue within dissociation and the system of care for it. Černis et al (2020) suggested that this difficulty in communication may also be maintained by fear, mental avoidance and concerns about others' reactions. As such, it was recommended that clinicians take on the initiative to proactively enquire about dissociative symptoms in order to target this trend of under-reporting. Given that General Practitioners (GPs) are often the first line of treatment for this population, additional training in recognising DPD and dissociative symptoms, particularly in children, may also be helpful in targeting this problem, especially since both CD and NC groups recognised DP symptoms emerging since childhood, usually as episodes of depersonalisation before the onset of chronic DP later in life. This is also supported by Baker et al (2003) who found that people with earlier onset of DPD tended to report more severe symptomology. Given this trend, earlier intervention in terms of psychoeducation and treatment may improve outcomes and potentially prevent the progression of the disorder.

Beliefs about treatment

Participants also report DP symptoms as maintained by stress, fatigue and awareness, which is in line with a CBT model of DPD (Hunter et al., 2003), similar to the CBT model for panic disorder (Clark, 1986) in which DP symptoms also often occur. This is particularly relevant for the SU group of DPD patients, who present with catastrophic appraisals of DP symptoms, relating the symptoms to beliefs about 'going mad'. Stress and fatigue increase the likelihood of negative catastrophic interpretations of DP symptoms. This may lead them to engage in safety and checking behaviours to 'appear or try to feel normal' such as excessive internal self-focus to monitor or ruminate on DP symptoms, increasing self-awareness of the symptoms. This inadvertently reinforces catastrophic misappraisal of DP symptoms, the salience of which is maintained in a vicious loop by excessive internal self-focus. Participants' subjective attributions may also potentially be understood from a longitudinal CBT perspective (Beck, 1993) as their childhood experiences form individualised core beliefs about the self, emotional expression and DP symptoms. The current research may be insufficient to fully elucidate and summarise common core beliefs of people with DPD, but the common pattern of emotional repression amongst DPD participants may suggest some internalised negative beliefs about emotional expression, whether that may be seen as a sign of weakness, frowned upon or socially unacceptable. This internalised aversion to emotional expression may potentially serve to maintain the DP symptoms in the vicious cycle described above, as DP, while distressing to participants, also serves the function of managing and suppressing overwhelming negative emotions and therefore may counter-intuitively be reinforced.

This may suggest that a CBT approach in treatment, while helpful for all participants in recognising and eliminating maintenance factors, may be particularly effective for DPD patients who attribute the onset of their disorder to substance use. This is also endorsed by Hunter et al (2005): her open study suggested that CBT may be an effective intervention for DPD, as 29% of participants no longer met criteria for DPD following treatment. It is worth highlighting, however, that our participants noted becoming more aware of these patterns of behaviour following treatment, which would be expected as the treatment provided at the DPD Service from which participants were recruited from follows a CBT structure as outlined by Hunter et al (2005). While some may argue that this finding is a result of confirmation bias, the nature of this study places an emphasis on the co-creation of meaning between the participants and the interviewer, and all results were derived from and grounded within the data. Nonetheless, as different beliefs and expectations of treatment appear to be associated with main attributions of DPD, this also suggests that an individualised approach to therapy may be more appropriate depending on the patients' needs. This is especially so for the group of DPD patients

who mainly attribute the onset of DPD to their childhood difficulties, and who describe experiencing a sense of 'readiness' before being able to meaningfully engage with therapy. This sense of 'readiness' appears to be linked to the need to address their childhood difficulties or traumas and overcome their self-hatred and low self-esteem in order to feel that they deserve to get better, and this process of gaining 'readiness' may potentially be achieved through other forms of therapy such as psychotherapy. This may suggest that prior to the commencement of CBT for DPD, the delivery of a course of emotional regulation, stabilisation, or even trauma-focussed therapy may be appropriate, depending on the individual presentation of the patient. This is supported by the trauma model of dissociation (Janet, 1903, 1928) in which presentations of dissociation were symptomatic of unresolved childhood trauma. This is also in line with Brand et al (2012)'s recommendations for staged treatment plans for dissociative disorders according to 3 phases: (1) skills building in maintaining psychological safety, emotional regulation and grounding; (2) tackling trauma-based cognitions through exposure and modified abreaction techniques; (3) less structured and individualised treatment. Further research into the developing trauma-informed strategies in fostering a sense of 'readiness', particularly for people with DPD, would be helpful in improving patients' relationships and engagement with therapy.

Limitations

As a constructivist theory, there is implicit and express recognition that construction of meaning is a partnership between the researcher and participants, within the context of the researcher's prior 'insider' knowledge and perspective, as well as the participants' subjective experience. As such, constructivist grounded theory does not aim for widely generalisable results, as the results of the study are always influenced by and understood within this specific context. This lack of generalisability is further magnified as the results are based on a sample that is recruited from a single clinical setting at a national specialist level. This convenience sampling likely influenced the pattern of participants recruited, such as being adequately functional to self-advocate for a referral to this clinic. Additionally, community samples of DPD patients may have differing experiences and outcomes due to inherent differences in their journey. However, given the high level of corroboration between the subjective experiences of participants and the body of literature as discussed above, we anticipate that this analysis offers a framework that may be helpful and transferable to other settings. While variation in the sample may not necessitate distinct clinical subgroups, especially when these results are understood and dependent on the specific context of this study, it is still meaningful to consider differences based on the subjective experiences and attributions of people with DPD, and the impact this may have on treatment.

Another limitation of this study was that data collection was not highly concurrent with analysis, potentially compromising the iterative process of constructivist grounded theory methodology. Although it was planned for data collection and analysis to run concurrently, delays to transcription and a limited time frame for data collection resulted in the bulk of formal data analyses taking place following the conclusion of data collection. However, careful consideration of the meaning of data throughout the data collection process, and regular memo-taking to capture reflections and thoughts of the researcher was applied to aid in the development of emerging themes. Application of an inductive methodology, albeit informally, also influenced the interview guide as it was amended and refined to capture emerging themes and concepts, such as the inclusion of personality types into the interview topic guide as interviews progressed.

Implications

We hope that this constructivist theory of common experiences and differing beliefs based on attribution of the disorder in DPD can be used as a starting point for clinicians to consider the importance of DPD patients' subjective experiences, and how the impact of those experiences play out in therapy.

As discussed above, the results of this study suggest that there may be sufficient justification for the following recommendations:

1. More training can be provided for GPs, as front-line clinicians, to recognise DPD, so as to decrease misunderstanding of symptoms.
2. Given participants' expressed difficulty in communicating and describing feelings of depersonalisation, clinicians can take on a more proactive role in asking about DP symptoms, as also supported by Černis et al (2020), so as to aid earlier identification of the disorder, especially for patients who identify with emotionally adverse childhood experiences and/or growing up in a high-achieving environment.
3. Clearer and more accessible instructions on referral pathways to appropriate support for DPD may help both patients and healthcare professionals in more efficiently streamlining DPD patients' journeys to appropriate support.
4. Allowing greater flexibility in therapy sessions in terms of length and scope, especially for people who identify with negative childhood experiences, may be helpful in building a stronger engagement with therapy, especially given how differing attributions and journey with DPD lead to varying attitudes and expectations of treatment.

Further research in the following areas have also been identified as potentially helpful developments in the field:

1. Effective identification of DP symptoms in children and/or adolescents, so as to enable earlier interventions (eg psychoeducation, emotional literacy and/or regulation etc) for people with emerging symptoms of DPD, and potentially produce better outcomes.
2. Effectiveness of prior emotional regulation/grounding work to improve readiness for and engagement with CBT-DP for people with emotionally aversive childhood experiences.
3. Effectiveness of imagery-based techniques for DPD patients in training emotional expression as a potential treatment method in reducing symptomology of DPD.
4. Potential effects of therapeutic interventions such as values-based therapy and assertiveness training in the cultivation of a stronger sense of self within DPD patients
5. An attachment perspective may be helpful to further explore the concept of self-identity and the impact of fantasy-proneness within DPD, and how these may impact on and play out within therapy.

Conclusion

In summary, DPD participants' subjective identification with emotional harm in their abusive or high-pressured childhood environments shapes their main attributions for the onset of their disorder, and accounts for the variance in their beliefs around the disorder and treatment. Through the constructive grounded theory, this study allowed for a deeper, more meaningful understanding of our participants with DPD, especially in terms of the perceived impact of their childhood and other stressors on the development of DPD, and their beliefs about treatment. This study also illuminates some clear recommendations and further research ideas based on the subjective experiences of our participants, which will likely be helpful to the wider DPD community.

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Appendix

Appendix A: Interview Guide v1

Interview Guide

- Introduce self and study
- Allow time/space for participants to ask any questions.
- Confirm following demographic information if not on epjs:
 - Age
 - Ethnicity
 - Education level
 - Occupation
- Confirm permission to start recording

Questions

1. **Experience of DP:** If I were to magically swap bodies with you, how would I experience a typical episode of depersonalisation? What would be different in terms of feeling/seeing/hearing etc?
2. **History/Impact of DP:** When did you start experiencing depersonalisation? How has that impacted on your everyday life? How do you think your background or cultural factors might have impacted on your experience of depersonalisation, if at all?
3. **Attributions of DP:** What do you think caused your episodes of depersonalisation? Was there anything that maintained these experiences or made it worse?
4. **Effect of substance use on DP:** Do you use any substances? How do you think your [substance] use affected your experience of depersonalisation, if at all?
5. **Effect of childhood experiences on DP:** How would you describe your childhood? Do you think your upbringing or childhood experiences has any impact on your experiences of depersonalisation, if at all?
6. **Diagnostic process:** What led you to decide to seek help for your experiences of Depersonalisation? What was it like to be diagnosed with Depersonalisation Disorder? What was the process of getting that diagnosis like for you?
7. **Beliefs about DPD:** If you were to meet another person with DPD, what are some assumed similarities/differences you may expect to have with that person?
8. **Attitudes about treatment*:** How do you feel about being treated for DPD? Do/Did you have any prior ideas/expectations of treatment? What has been different for you since ending treatment? What do you think led to that change?

**questions may be adapted based on their stage in receiving help*

9. **Ending question:** Is there anything else relevant about your experience of Depersonalisation Disorder that I have not asked you about?

Appendix B: Interview Guide v4 (final)

Interview Guide

- Introduce self and study
- Allow time/space for participants to ask any questions.
- Confirm following demographic information if not on epjs:
 - Age
 - Ethnicity
 - Education level
 - Occupation
- Confirm permission to start recording

Questions

10. **Experience of DP:** If I were to magically swap bodies with you, how would I experience the feelings of depersonalisation? What would be different in terms of feeling/seeing/hearing etc?
11. **History/Impact of DP:** When did you start experiencing depersonalisation? How has that impacted on your everyday life?
12. **Attributions of DP:** What do you think caused your episodes of depersonalisation? Was there anything that maintained these experiences or made it worse?
13. **Effect of childhood experiences on DP:** How would you describe your childhood? Do you think your upbringing or childhood experiences has any impact on your experiences of depersonalisation, if at all? How do you think your background or cultural factors might have impacted on your experience of depersonalisation, if at all? *Emotional suppression/repression?*
NB: to be ask with sensitivity, reiterating participants' right to not answer if uncomfortable
14. **Effect of personality?**
15. **Effect of substance use on DP:** Do you use any substances? How do you think your [substance] use affected your experience of depersonalisation, if at all?
16. **Diagnostic process:** What led you to decide to seek help for your experiences of Depersonalisation? What was it like to be diagnosed with Depersonalisation Disorder? What was the process of getting that diagnosis like for you? How did that impact on your relationship with healthcare professionals?
17. **Beliefs about DPD:** If you were to meet another person with DPD, what are some assumed similarities/differences you may expect to have with that person?

18. **Attitudes about treatment***: How do you feel about being treated for DPD? Do/Did you have any prior ideas/expectations of treatment? What has been different for you since ending treatment? What do you think led to that change? What do you think treatment for DPD should look like to you?

**questions may be adapted based on their stage in receiving help*

19. **Ending question**: Is there anything else relevant about your experience of Depersonalisation Disorder that I have not asked you about or you felt was really important for me to understand?