"I no longer remember what it feels like to be me": Experiences of identity in waking and dreaming life in people with depersonalisation-derealisation disorder

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Abstract

Depersonalisation-Derealisation Disorder (DPDR) is a dissociative condition characterised by persistent, distressing feelings of detachment from oneself or the external world (Yang et al., 2022). Despite growing recognition of the profound disruptions to the sense of identity in people with DPDR, existing research largely relies on quantitative methods to understand DPDR symptomology, leaving significant gaps in our understanding of the subjective, lived experiences of those affected. Limited qualitative studies have begun to explore DPDR experiences, though more broadly, rather than specifically examining the construct of identity. This study addresses this gap, making it the first to qualitatively explore how individuals with DPDR experience their sense of identity when awake and in their dreams.

Twelve in-depth interviews were conducted using the free-association narrative interview method with individuals diagnosed with DPDR. The interviews aimed to uncover how participants perceive and navigate their sense of identity in both waking and dreaming life, considering the potential for unique insights dreams may offer into self-perception. Using narrative analysis, the study identified three overarching narrative types in participants' stories, each with two subthemes: narratives of *Constancy and Change Across Time* ('Loss of pre-DPDR self and attempts to reconcile with the present' and 'Similarity between pre and post-DPDR sense of self), *Intersubjectivity* ('Faking a sense of self and doing what is expected' and 'Interpersonal situations which strengthen or weaken sense of self', and *Agency* ('Taking control vs feeling powerless' and 'Waking life as scary and dreams as a safe space to regain agency').

This study contributes to narrative theory and theories of identity and dreams as well as the literature on lived experiences of DPDR while challenging the sleep continuity hypothesis. The implications for clinical practice suggest therapeutic approaches could benefit from addressing identity-related concerns and incorporating the interplay between waking and

dreaming experiences. Overall, this research provides a foundation for a holistic, person-centred approach to understanding and treating DPDR outside of the dominant trauma-focussed narrative.

Introduction

1.1 Chapter Summary

This chapter provides the introductory context for the present study by reviewing the construct of Depersonalisation-Derealisation Disorder (DPDR). It recognises the impact of DPDR on people's sense of self and wellbeing and provides a critical overview of the challenges to receiving a diagnosis and treatment. Various opposing theories which create an ununified understanding of the disorder – and thus contribute to difficulties in diagnosing and treating DPDR – will be outlined. Finally, there is a focus on how dreams and sense of self are experienced and understood in DPDR. The latter half of this chapter presents a systematic literature review investigating the lived experience of DPDR using qualitative studies. The gaps in research identified by the literature presented and systematic review are highlighted to provide a rationale for the current study.

1.2 DPDR

1.2.1 History of DPDR

The American Psychiatric Association (APA) define dissociative disorders as involving a disruption of and/or discontinuity in the normal integration of consciousness, memory, identity, emotion, perception, body representation, motor control, and behavior", and identify three main types of dissociative disorders: dissociative identity disorder (DID), dissociative amnesia and DPDR (APA, 2022).

Historically, dissociation has been difficult to describe and assess. In the late 1800s, seizures and other dissociative symptoms were commonly grouped together and referred to as "hysteria" (Cassady & Baslet, 2023). Symptoms of depersonalisation were first written about in the early nineteenth century (Sierra & Berrios, 1997), and over the years, conceptualisations of the disorder have varied greatly. Though written about, the term depersonalisation was not coined until 1898 by Dugas, in exploring the psychopathology of "false memories". The term

was taken from the diary of Swiss philosopher, H.F. Amiel who wrote: "Everything is strange to me, I can be outside of my body, of me as an individual, I am depersonalized, detached, away" (Amiel, 1927, p288). Throughout the next century, many theories attempted to explain these symptoms, including that depersonalisation is an evolutionary response to survive, and can be triggered by threat or danger (Roth, 1959), or as a precursor of depression (Esquirol, 1938). Other early theories included the sensory hypothesis, which viewed feelings of unreality as the result of a dysfunctional sensory system (Krishaber, 1873).

It wasn't until the early twentieth century that the term derealisation was introduced by Mayer-Gross (1935), to distinguish whether feelings of unreality referred to the self or one's surroundings. While some argue DPDR has only recently gained attention in clinical research, symptoms of dissociation – and DPDR in particular – have long been debated among psychoanalytic theorists, primarily using individual case studies, which Doherty (2014) argues have made the most significant contributions to our understanding of the disorder.

The transdiagnostic nature of dissociation adds to long-standing difficulties in defining DPDR and recognising it as a disorder in its own right. For example, a meta-analysis of dissociative experiences in psychiatric disorders found the highest scores of dissociation according to the Dissociative Experiences Sale (DES; a scale used to measure DPDR) were in people with DID, followed by post-traumatic stress disorder (PTSD), borderline personality disorder (BPD), functional neurological disorder, somatic symptom disorder and substance use disorders (Lyssenko et al., 2018). Other neurological disorders reporting dissociative experiences include epilepsy, cerebrovascular disease, migraine, vertigo and temporal lobe neoplasms (Lambert et al., 2002). Clinically and academically, much of our knowledge about dissociation stems from trauma-related studies, with PTSD having its own dissociative subtype, D-PTSD (Brand & Frewen, 2017).

The two manuals used to guide diagnosis of mental health conditions are The Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2022) and the International Classification of Diseases (ICD-11; World Health Organization, 2018), with the former being used in the United States and the latter in the UK. It was not until the DSM-5 published in 2013 that the term DPDR was first introduced. Prior to this, it was referred to as depersonalisation and considered a form of neurosis in the DSM-II (1968) and only recognised as a dissociative disorder in the DSM-III in 1980. Overall, both manuals agree over the diagnostic criteria for DPDR, in that symptoms should be persistent and not part of other disorders including psychosis (Medford, 2012). Key differences include that the ICD classifies DPDR under "other neurological disorder", rather than dissociative disorder (WHO, 2018). Furthermore, the ICD describes dissociation as an acute disorder that usually occurs after a stressful or traumatic experience, and that it remits after a period of a few weeks or months, while the DSM conceptualises it as a chronic, long-term condition (Spiegel et al., 2011). These differences contribute to the confusion as to the cause and course of DPDR.

However, dissociative experiences are recognised to occur on a spectrum, not only pathologically. For example, daydreaming or losing track of time whilst absorbed in a task are seen as normal dissociative experiences among the general population (Cassady & Baslet, 2023), while pathological experiences cause impairment to daily functioning.

1.2.2 Prevalence, Symptoms and Impact

For people with DPDR, moving through and existing in the world is marked by persistent distressing feelings of unreality or detachment from one's self or the world (APA, 2022). Despite high prevalence rates, similar to those of schizophrenia, there is a dearth of research into DPDR lived experiences (Yang et al., 2022).

The onset of DPDR is most commonly before 25 years and rarely after 40 (Baker et al., 2003). Symptoms have been linked to experiences of traumatic events, with the highest rates found in people who have experienced interpersonal abuse (25–53.8%; Yang et al., 2022). Trauma is defined as a stressful event (short or long-lasting) of exceptionally threatening or catastrophic nature, and it is the persistent re-living of this event which qualifies as a diagnosis of PTSD (WHO, 2018). However, trauma is not a necessary precursor for developing DPDR which has also been diagnosed in otherwise healthy individuals during times of acute stress (Yang et al., 2022). It follows that DPDR prevalence statistics vary greatly. The most recent systematic review found DPDR was more prevalent among people with a mental health diagnosis (1.8%-53.8%) than the general population (Yang et al., 2022), with average prevalence rates estimated to range from 0.95-1.9% in general population samples from the UK and Germany respectively (Wang, 2024). Cassady and Baslet (2023) however, have reported that lifetime prevalence of DPDR symptoms range from 26-70% in the general population, supporting the idea of dissociation as a normal part of human experience.

Importantly, DPDR symptoms differ from DID and dissociative amnesia. DID was previously referred to as 'multiple personality disorder' and those affected may experience gaps in memory as well as several distinct identities, each with their own names, voices, personal histories and mannerisms. Dissociative amnesia is characterised by severe gaps in memory, such as about themselves or things they have done (NHS, 2023). DPDR symptoms can be transient or enduring and cause functional impairment (APA, 2022). Those most commonly experienced were categorised by Ciaunica et al. (2023) as (a) '*sensory and bodily aspects of oneself*' (detachment from one's body or body parts); (b) '*experiential aspects'* (detachment from one's subjective feelings and emotions); and (c) '*cognitive and narrative aspects'* (disconnection from one's personal stories, memories, thoughts and future plans). Other symptoms include changes to the intensity of sensations such as sounds, tastes, textures,

smells and colours and as a result, DPDR patients report experiences such as feeling the world lacks in depth and vibrancy or that places and objects are unfamiliar. Patients have also described a lack of ownership over their thoughts and experiences, sometimes feeling unable to move their own body intentionally or lacking strong emotional reactions. Some have reported feeling older or younger than their actual age (Ciaunica et al., 2023).

Sense of time has commonly been reported to change, both implicitly (in the moment) and explicitly (reflecting on our past and future; Fuchs & Van Duppen, 2017), such as moving faster or slower than expected or like time has stopped, and difficulty focussing on anything other than the present. This is because the future invokes a sense of disconnection or anxiety, as though it may not occur. For some, the past feels distorted as to when events occurred. Others describe an intense re-experiencing of past memories. Factor analysis studies have found the five symptoms which characterise DPDR (numbing, unreality of self, unreality of other, temporal disintegration, and perceptual alterations) are equally present regardless of whether DP or DR is most predominant (Fagioli et al., 2015).

The impact of DPDR on mental and physical health are far reaching. Depersonalisation correlates highly with anxiety and depression, which is experienced as feelings of panic attacks or helplessness (Baker, 2003; Wang, 2024). People with comorbid depression and DPDR were found to experience more prolonged and intense symptoms of depression over a five-year study, with only a 6.9% remission rate, suggesting DPDR may play a causal role in depression, rather than only being a symptom of it (Michal et al., 2024). Those with and without depression also experienced worse self-rated physical health, regardless of age and major medical diseases. Furthermore, dissociative symptoms degrade quality of life (Polizzi et al., 2022) and are associated with enduring impacts including recurrent hospitalisations, suicide, and high rates of disability (Langeland et al., 2020).

Unfortunately, due to the overlap of DPDR symptoms with other conditions, as well as a possible lack of understanding from clinicians about the disorder (Renard et al., 2017), people wait an average of 7-14 years between the onset of DPDR and receiving a diagnosis (Baker et al., 2003; Michal et al., 2016). This lack of understanding may also be responsible for misdiagnosis and mistreatment, which contributes to an economic burden on the NHS and healthcare systems worldwide (Langeland et al., 2020). Adding to this, there is only one specialist DPDR NHS clinic in the UK. Located in South London, The Maudsley only treats adults, and with limited resources, fewer than 80 patients a year can be seen (Victoria Derbyshire, 2017).

1.2.3 Diagnostic Scales

The frequency and severity of DPDR symptoms can be measured using various tools designed for dissociative disorders generally or DPDR specifically. Currently, there are no NICE guidelines dedicated solely to the assessment and treatment of dissociative disorders, including DPDR. However, The Structured Clinical Interview for DSM-IV Dissociative Disorders (SCID-D; Steinberg, 1994) is a semi-structured interview designed to diagnose dissociative disorders. With over 30 years of research validating its use cross-culturally, the SCID-D widely recognised as the gold standard in assessing dissociative disorders (Steinberg, 2023). It assesses five areas: amnesia, depersonalisation, derealisation, identity confusion and identity alteration, and includes follow-up questions about symptom experience, frequency and impact (IISTD, 2011).

Many other non-diagnostic tools have been validated, though these are designed to track symptoms over time or as a brief screening tool (IISTD, 2011). One of the most common is The Dissociative Experiences Sale (DES), a 28-item self-report scale which differentiates DPDR from other disorders such as dissociative amnesia or DID (Doherty, 2014). While the

DES measures symptom duration, it does not measure frequency, leading to the development of The Cambridge Depersonalisation Scale (CDS; Sierra & Berrios, 2000). This quantitative instrument differentiates between DPDR as a primary or secondary diagnosis, with people who have anxiety or other mood-related diagnoses scoring lower on the CDS compared to those diagnosed with primary DPDR (Hunter et al., 2004a). Both the DES and CDS assess symptoms over the last six-months, therefore The Structured Clinical Interview for Depersonalisation-Derealisation Disorder (SCI-DER; Mula et al., 2008) was developed to measure symptom presence over the lifetime whilst collecting rich insights into impact and cause.

One of the major limitations of the DES is that it omits some core experiences of dissociation, most notably emotional numbing (Černis et al., 2021). To combat this, The Černis Felt Sense of Anomaly (ČEFSA; Černis et al., 2021) was developed. The seven-factor screening tool measures an altered sense of familiarity, connection, agency and reality, and anomalous experiences of the self, body and emotion; capturing experiences which are less severe or difficult to articulate such as "I feel like I don't have a personality" (Černis et al., 2021). It has been validated in clinical and non-clinical populations.

1.3 Theories of DPDR

Multiple theories of DPDR exist. Covering all of these is outside the scope of this research, however, the three main theories which will be covered include psychoanalytic theory, the cognitive-behavioural model and the post-traumatic model of DPDR.

1.3.1 Psychoanalytic Theory of DPDR

Numerous, conflicting psychoanalytic perspectives of DPDR exist, making it difficult to offer a unified summary (Sierra, 2009). Furthermore, these theories focus on depersonalisation rather than derealisation or the co-occurrence of both. However, they

generally converge on the idea that DPDR serves as a defence mechanism against psychic conflicts that threaten the integrity of the self (Medford et al., 2005). This understanding is rooted in the early work of Sigmund Freud and other notable psychoanalytic theorists, during the late 1800s and early 1900s when dissociation theory was first developing (Doherty, 2014).

Freud (1941) first discussed dissociation by referring to it as repression. Describing his own experiences of depersonalisation, Freud concluded his experience was the result of his mind defending against feeling triumph and guilt for superseding his father (Doherty, 2014). The idea of dissociative experiences acting as a defence against affects was supported by other psychoanalytical theorists including Fenichel (1945) and Sadger (1928). Similarly, Bradlow (1973) viewed DPDR as a defence against negative affect, and theorised the psychodynamics of 'not feeling human' are *always* connected to feelings of shame. Specifically, depersonalisation is the result of moral inferiority, where there is a disconnect between who someone is and who they wish to be. He postulated those suffering depersonalisation are "shame-ridden and prone to react with disgust, aversion, horror and self-contempt" (p490).

Other psychoanalysts were less specific about which emotions DPDR protects against; referring to general negative affect. Fenichel (1945) believed prior to depersonalisation, an increased focus on the self results in perceptions and emotional experiences that the ego finds unpleasant or intolerable, such as shame or inadequacy, which threatens one's self-concept. Thus, the ego undertakes defensive measures to protect itself from experiencing these uncomfortable emotions.

Other psychoanalytic theorists focussed on the disruption to development at key life phases, particularly early childhood, as being the root cause of depersonalisation. Schilder (1939) spoke of depersonalisation as a developmental syndrome which forms as a reaction to parental affection being withdrawn as one ages. He posited depersonalisation affects children who have been overly admired for their looks and intelligence and expect this inflow of

attention to be continuous. They view the lessening of this attention as neglect and begin to overly self-observe in replacement, though this gives way to hypochondriac concerns. He writes: "Depersonalization is the neurosis of the good looking and intelligent who want too much admiration" (p260). This theory however, fails to explain why children who are the victims of parental abuse later develop depersonalisation and at a disproportionately higher percentage compared to those who were not abused. Analytical theories have also been criticised for largely being based on a select few patients (Ackner, 1954), nonetheless, as with the current study, an in-depth exploration of individual experiences or smaller samples provides rich qualitative insights that may not emerge in larger-scale studies.

In a review of psychoanalytic theory, Torch (1978) summarises that self-observation is often listed as resultant symptom of depersonalisation, when in fact it is a primary cause, as most people who experience depersonalisation have obsessional personality types; focussing their anxiety on themselves and questions of who they are. He further commented how this is more common in young men, specifically philosophers, mathematicians, psychologists and psychiatrists who are prone to ruminate on the intrinsic meaning of things.

1.3.2 Post-Traumatic Model (PTM) of Dissociative Disorders

While many psychoanalytic theories view DPDR as an active process, Janet (1889) suggested DPDR can occur passively. In coining the term "subconscious", referring to memories which are automatically stored (Van Der Kolk & Van Der Hart, 1989), Janet moved away from the idea of depersonalisation actively defending against negative emotions, and explained passive ways the disorder can manifest. He believed when traumatic memories are too difficult to confront, they split off from consciousness and are stored in the subconscious, however, failure to integrate these memories with the present disrupts a sense of equilibrium and prevents adaptation to reality (1889). Although subconscious, these memories continue to

influence current perceptions, affect and behaviour as they diminish one's capacity to deal with current reality (Van Der Kolk & Van Der Hart, 1989). Janet's theory pioneered current understandings of dissociation from a post-traumatic view, though not DPDR specifically. Overall, dissociation is viewed as a protective mechanism, as depersonalisation protects individuals from experiencing emotional pain by downregulating the limbic system (Lanius et al., 2010), while derealisation protects people by distorting the outside world to make the source of one's trauma seem less real (Watson, 2022).

Supporting this, a review by Yang et al. (2022) found DPDR was consistently linked to having experienced interpersonal abuse. Furthermore, symptoms of depersonalisation are commonly experienced during or immediately after traumatic events, which is often referred to as "peri-traumatic dissociation" (Doherty, 2014). This relationship between childhood trauma and PTSD symptoms have been found to remain related to dissociative experiences whilst controlling for other factors such as emotional dysregulation, alexithymia and impulsivity (Powers et al., 2015; Terock et al., 2016), suggesting a causal pathway between trauma and dissociation. Similarly, Dimitrova et al. (2020) used statistical models to delineate that fantasy proneness and sleep disturbances were only related to dissociation when childhood trauma was included in the model. However, evidence such as this highlights a weakness of the PTM, in that it does not explain whether the effects of trauma are direct or indirect and how or why they can be moderated or mediated by other variables mentioned (Lynn et al., 2022).

The biggest criticism of the PTM is that general psychological distress, not just trauma, can contribute to dissociative experiences. Lynn et al. (2022) cite several studies showing anxiety, depression and hostility can predict dissociation even when controlling for trauma (Aksen et al., 2021; Condon & Lynn, 2014; Evren et al., 2013; Soffer-Dudek, 2017; Weiss & Low, 2017). Though DPDR is often central to PTSD, symptoms are also present in panic disorder and may result from overwhelming negative emotions rather than trauma (Soffer-

Dudek, 2017), discussed further in the cognitive-behavioural view to follow. Additionally, increased rumination has been linked to long-term DPDR symptoms (Buchnik-Daniely et al., 2021). Critics also note methodological issues in trauma-dissociation studies, including reliance on cross-sectional designs and retrospective, uncorroborated self-reports, which can inflate trauma-dissociation correlations due to demand characteristics and measurement of both in the same context (Lynn et al., 2022; Patihis & Lynn, 2017). The PTM does not clearly define what constitutes a traumatic event or specify if trauma is necessary or sufficient for dissociation, thus making it difficult to discern what evidence would count against it (Lynn et al., 2022). Finally, the model does not address why some individuals develop dissociation as a defence mechanism while others do not.

1.3.3 Cognitive-Behavioural Model of DPDR

More recently, a cognitive-behavioural model of depersonalisation was proposed (Hunter et al., 2004b). Unlike the previous theories, this model aims to explain why DPDR persists, rather than offering an explanation as to how it arises (Medford et al., 2012). At the heart of this model is the idea that anxiety – specifically panic – and depersonalisation are intrinsically linked, and that DPDR is most suitably understood as an anxiety disorder rather than dissociative condition (Hunter et al., 2004b). This is because the cognitions and behaviours central to anxiety are those which exacerbate and perpetuate DPDR symptoms. Notably, depersonalisation and derealisation are two of the symptoms of panic according to the DSM-IV (APA, 2022). However, this model primarily addresses the anxiety-related cognitions which arise as a *result* of DPDR, rather than the actual experiences themselves, and does not explain other symptomatic experiences such as emotional or somatic features of DPDR (Medford et al., 2012).

Hunter et al. (2004b) outline the panic-related cognitions which they believe fuel DPDR, including catastrophic appraisal of normally transient symptoms. These appraisals are similar to those seen in health-anxiety, such as misinterpreting symptoms as being indicative of something more severe such as brain dysfunction or the belief that one is 'going mad', which has been noted to occur in several DP patients in papers by Roth (1959) and Ackner (1954). Hunter et al. (2004b) explain these beliefs create a vicious cycle whereby these thoughts increase anxiety, which worsens DPDR symptoms, which in turn increases anxiety; an idea supported by the prominent cognitive-behaviouralists in the field of panic (Clark & Wells, 1995).

Another trait of anxiety which perpetuates DPDR is avoiding situations which cause anxiety ('safety behaviours'), which prevents people from ever disconfirming their catastrophic misinterpretations (Hunter et al., 2004b). Social avoidance is a core tenet of agoraphobia, an anxiety and panic-related disorder, and is commonly seen in DPDR, as many people describe avoiding social situations for fear of being judged by others or because crowded environments may intensify DPDR symptoms (Roth & Argyle, 1988). Fittingly, Simeon et al. (1997) found nearly half of those with DPDR had a co-morbid diagnosis of social phobia. Finally, cognitive bias is the idea that one disproportionately pays attention to things which confirm one's prior beliefs, and is another cognition which Hunter et al. (2004b) say maintains DPDR, by increasing awareness of symptoms which heightens its perceived threat. A diagram illustrating this cognitive-behavioural conceptualisation of DPDR can be seen in figure 1 below.

Figure 1

Cognitive-Behavioural Conceptualisation of DPDR (Hunter et al., 2004b)

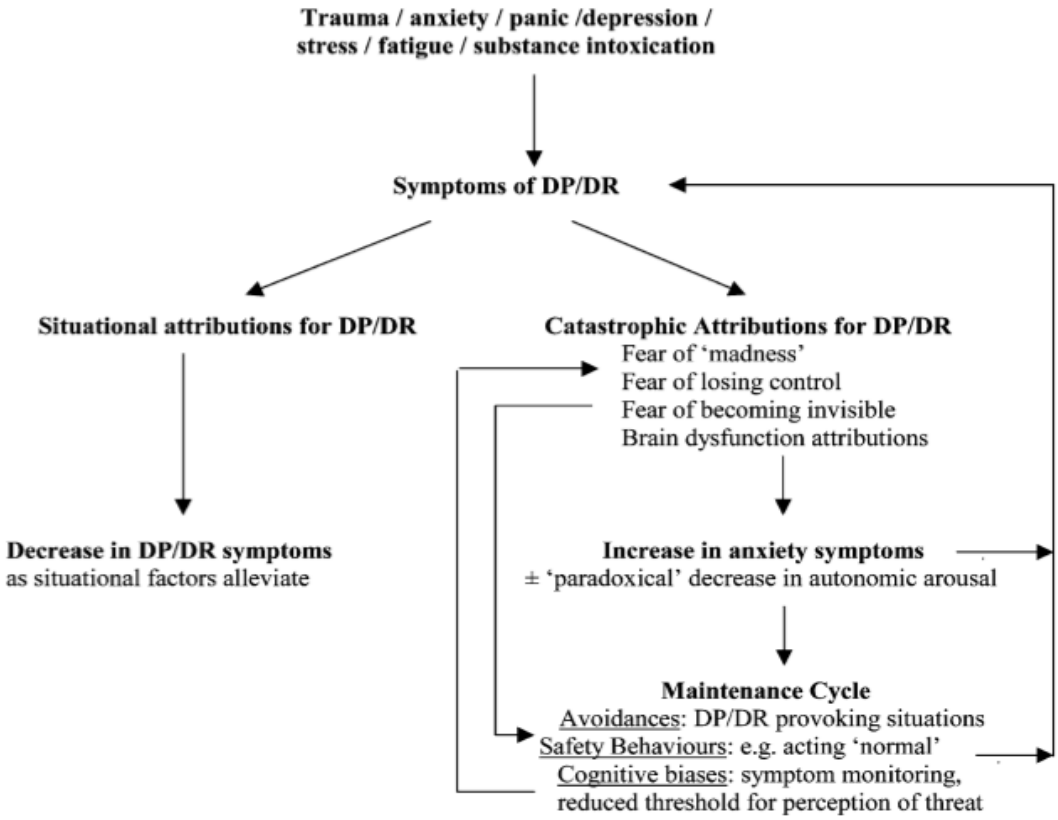


Fig. 2. Cognitive–behavioural model of depersonalisation disorder

Figure 1 shows the intensification of DPDR symptoms as a result of anxiety which importantly is located *internally*, which explains why attributing ones anxiety to external, situational factors, reduces anxiety and DPDR symptoms. Research lends support to the idea of internalisation of anxiety in DPDR. For example, interviews with 15 DPDR patients found those who experienced DPDR as a transient condition attributed their symptoms to temporary

factors such as fatigue, stress, drug use, or situational fear, and believed symptoms would end once the circumstances which caused them improved (Ackner, 1954). Conversely, more than half of those with chronic DPDR had close family members who had psychosis, and six reported preoccupation with fears of insanity prior to DPDR onset. Ackner (1954) believed this contributed to a pre-existing anxiety about mental health and belief they were more vulnerable or predisposed to experience mental illness. Thus, these people interpreted their symptoms as more alarming due to their apparent confirmation of their pre-morbid beliefs.

However, while evidence supports the link between anxiety and DPDR, some studies demonstrate not all people experience DPDR as anxiety-provoking. For example, qualitative accounts from Pienkos and Sass' study (2022) and Watson's autoethnography (2022) describe an acceptance or even appreciation of DPDR, for example its ability to reduce anxiety in situations they would otherwise have found stressful. Yet they continue to experience chronic symptoms.

1.4 Treatment

Current treatment guidelines reveal significant gaps, partly due to the conflicting theories surrounding DPDR. Doherty (2014) found that clinicians' knowledge of dissociative disorders significantly influenced diagnostic accuracy, with limited understanding often resulting in misdiagnoses and incorrect treatments focused on anxiety or trauma instead.

DPDR is frequently presented as a rare condition, resistant to therapeutic intervention (Doherty, 2014) and a manual search of NICE guidelines by the researcher did not retrieve any specific treatment for DPDR, but instead showed treatment recommendations for PTSD (NICE, 2018). Within this, 'chronic dissociation' and depersonalisation are mentioned but as a symptom of PTSD rather than a stand-alone disorder, and derealisation was not mentioned.

Within these recommendations, there remained debate as to whether PTSD itself is classed as a dissociative disorder or an anxiety disorder, impacting the type of treatment recommended.

The NHS broadly suggests talking therapy, antidepressants, or Eye Movement Desensitisation and Reprocessing (EMDR, a type of trauma therapy) for dissociative disorders but not specifically DPDR (NHS, 2021). In a 2019 parliamentary debate, challenges in diagnosing and treating DPDR were highlighted, including a lack of awareness among healthcare professionals, leading to misdiagnosis and ineffective treatment. Recommendations included improving professional training, establishing specialised services, ensuring access to treatment for adolescents, and raising public awareness (Hansard, 2019). While organisations including Unreal Charity and the Maudsley Hospital have made independent efforts to support individuals with DPDR and raise public awareness, the need for comprehensive government action remains.

DPDR treatment research is limited and inconclusive. Cognitive-behavioural therapy (CBT) has been suggested (Hunter et al., 2004b), particularly models focusing on anxiety. Techniques include psychoeducation and normalising experiences, diary-keeping (to identify patterns, links between thoughts, behaviour and change/variability in symptoms), reducing avoidance, reducing self-focussed attention through grounding techniques, challenging catastrophic assumptions and reality testing (behavioural experiments). However, the effectiveness of CBT for DPDR has been questioned, as dissociation can predict poorer treatment outcomes and is linked to higher relapse rates (Doherty, 2014; Rufer et al., 2006). Doherty (2014) suggests psychodynamic therapy offers potential, but there is insufficient research on its benefits for DPDR. Additionally, the role of sociocultural factors such as race, class, ethnicity and gender on treatment outcomes is underexplored (Doherty, 2014).

A systematic review of treatments for DPDR by Wang et al. (2024) found 30 methods had been applied independently or in combination to treat DPDR since 1955. Medication was

the most common approach, including anti-depressants, antiepileptics and antipsychotics. Regarding sense of self, EMDR reversed sensory and cognitive numbing and helped individuals recover a sense of familiar self by targeting 'dysfunctional breathing' patterns such as by holding ones breath (Hollander, 2009). However, they concluded the lack of high-quality evidence and standardised outcome measures make it difficult to develop definitive treatment guidelines; ultimately impacting clinicians' ability to make appropriate clinical decisions.

1.5 DPDR and Dreams

1.5.1 The Sleep Continuity Hypothesis

The dreamlike quality of DPDR symptoms has sparked interest in sleep and dreams (Bob, 2004; Giesbrecht & Merckelbach, 2004; Watson, 2001), with patients often quoting that DPDR is 'like living in a permanent dream' (Sirvent & Fernandez, 2015). Dreams have been likened to a normal experience of dissociation in the non-clinical population, and normalises experiences of distorted sense of time, space and orientation, or viewing oneself from outside of one's own body (Gabel, 1990). For example, in dreams a sense of the past, present and future may be experienced as overlapping windows rather than linear (Macduffie & Mashour, 2010), which mirrors symptoms experienced by people with DPDR in waking life (Moiseeva, 1975).

Research and theory suggest dissociation may be exacerbated and maintained by a 'labile sleep-wake cycle'; sleep that is disrupted or a lack of sleep. It is hypothesised that disturbing one's sleep cycle promotes the intrusion of dreamlike experiences – such as feelings of depersonalisation and out-of-body experiences – into waking consciousness (Van Der Kloet et al., 2012a). This is thought to be compounded by the potential negative impact of a labile sleep cycle on memory and attention, found to be impaired in those with DPDR (Van Der Kloet et al., 2012a). This continuation of dissociative experiences in waking and sleeping states is known as The Continuity Hypothesis (Schredl & Hofmann, 2003), and has been accepted as an explanation as to why people with dissociation report more nightmares and frightening or

stressful dreams (Cheung, 2012). It views a disturbed sleep-wake cycle as a necessary trigger of dissociative symptoms when awake.

A correlation between dissociation and disturbed sleep is well supported, with sleep experiences explaining more variance in dissociation than factors otherwise correlated with dissociation including impulsivity, emotion dysregulation, neuroticism, alexithymia and negative affect (Aksen et al., 2021). For example, dissociative symptoms have been related to self-reports of vivid dreams, nightmares (Levin & Fireman, 2002), recurrent dreams and hypnopompic imagery (hallucinations experienced as one is waking up, including seeing moving shapes, colours or imagery; Watson, 2001) and difficulty discriminating between vivid dreams and reality (Rassin et al., 2001). On the other hand, Erdeniz et al. (2023) found high levels of bodily awareness in dreams was associated with high levels of dissociation when awake, suggesting the opposite of the continuity hypothesis is true for some people.

Linking trauma, dissociation and sleep together, Molina (1996) found higher DES scores correlated significantly with higher early childhood trauma scores. Dreams in these individuals reflected a fragile and threatened sense of self. The converse is also supported, in that improved sleep hygiene led to reduced dissociative psychopathology after 6-8 weeks (Van Der Kloet et al., 2012b).

A criticism of these studies is that it is unclear which symptoms of dissociation or DPDR are impacted by disturbed sleep, especially as the majority of studies reviewed by Van Der Kloet et al. (2012a) use the DES but report overall symptom changes rather than specific symptoms. Furthermore, the link between dissociative symptoms and sleep disturbances is correlational, therefore it is unclear exactly how they impact each other, for example, whether waking experiences also contribute to difficulties sleeping, and thus constitute a bidirectional relationship between sleep and dissociation. Importantly, these studies are in people who experience dissociation, not DPDR specifically. To date, only one study has explored the link

between waking and dreaming experiences in people with DPDR (Gwyther et al., 2023). They found mixed results in support of the sleep-continuity hypothesis. In support, people scoring higher on the CDS were more likely to experience dreams from an outsider perspective though the correlation for this was weak-moderate. However, there was no significant correlation found for the statement "In my dreams I am aware of the presence (or absence) of my body", meaning those with higher scores of DPDR did not show disturbances to their bodily perception in their dreams which one would expect if there were continuity between waking and dreaming experiences.

1.5.2 Dreams and Sense of Self

Within dream research, one of the main areas of interest is how dreams relate to understanding and representing a sense of self. Clinically, dreams have long been a source of interest, particularly in psychoanalytic practice (Gabel, 1990) which uses free association as a method of exploring dream content. The first recorded psychological investigations into free association were conducted by Francis Galton (Galton, 1879a, 1879b), though it is now most commonly associated with Freud, after free association became the fundamental rule of psychoanalysis (Freud, 1899). During free association, analytical patients are encouraged to share their thoughts freely, regardless of how irrelevant or disagreeable they may seem. It was thought the connections between a seemingly illogical sequence of ideas would reveal unconscious conflict at the root of a person's difficulties. As early as 1910, dreams of people with personality disorder were explored through free association, thought to be the most appropriate method for "resurrecting dissociated memories", (Prince, 1910, p144), which Prince (1910) believed represented people's mental attitude towards their environment or problems in daily life.

This pathological view of dreams has since evolved, with many believing dreams are a window to understanding one's sense of self (Gabel, 1990). As discussed, people with DPDR have a fragmented and unstable sense of self, and relatedly, within psychoanalytic dream literature, Kohut (1977) believed the function of dreams is to heal and reintegrate the self to achieve a sense of continuity when the self is threatened by dissolution or fragmented. He termed these dreams 'self-state dreams', and believed they reflected one's "dread of the dissolution of the self" (p109). Adding to this, Stolorow and Atwood (1989) explained these dreams attempt to achieve more stable sense of self by focussing one's anxiety on the dangers it faces, making them clear in the person's mind. They therefore bring a sense of reality by transforming complex and intangible emotions, thoughts and states of mind into perceptible, vivid images that can be processed and understood.

More recently, Hollan (2004) coined the term 'selfscape dreams' to refer to vivid and emotionally-charged dreams which he argues "reflect back to the dreamer how his or her current organization of self relates to various parts of itself to itself, its body, and other people and objects in the world" (p. 172). Hollan (2004) suggests dreams assess and reflect the relative health and well-being of the self; a view supported by other psychoanalytic thinkers such as Fairbairn (1952). Such vivid dreams are cited in the literature above as common in people with DPDR.

Another theory which views the function of dreams as helping achieve a stable sense of self comes from Damasio (1994; 1999), whose theory extends our understanding of the self as encompassing an awareness of bodily experiences. According to Damasio (1994), our understanding and awareness of ourselves are grounded in how our body experiences and engages with the environment. He posited our representations of the body, self and world must be continuously updated and modified through our dreams, and that this dynamic process is

necessary because our body and environment are constantly changing. These updates ensure our perceptions and self-awareness remain accurate and relevant.

While these writers did not explicitly relate their theories to dissociation or DPDR, these psychoanalytic concepts may offer an alternative explanation to the continuity hypothesis about the function of dreams in people with DPDR. Rather than dissociative symptoms simply spilling over from waking life, fragmented and vivid dreams in people with DPDR may reflect their attempt to represent their sense of self and their body, or to heal the dissolution that threatens them.

1.5.2.1 Exploring Identity and Dreams in Research

Although there has been a shift to understanding the mental organisation of the self both clinically and in research through dreams, this has not been done in the field of dissociative disorders. Gabel (1990) called for the need to understand dissociation from perspectives outside of the dominant psychopathology lens and proposed that dreams be a way of doing this. Despite this, while research has begun to explore the link between DPDR and disturbed sleep, this research is quantitative, ignoring the contents of dreams and the potential link this may have to one's waking experiences or the impact on sense of self. These are gaps which the current study fills.

Of the qualitative research into dreams and identity which has been done outside of DPDR, narrative methods such as open-ended interviews or dream diaries are predominantly used, mirroring the free association techniques used in clinical practice (Ellis, 2016; Jović et al., 2018; Lee, 2018; Marogna et al., 2021). In research, 'narrative' refers to storytelling (Parks, 2023); a fundamental human experience used to connect with others and understand oneself (McLean & Syed, 2015). Narratives are intimately connected to how we conceive of and understand identity (Sfard & Prusak, 2005; Swain et al., 2015), as it is through storytelling that

"people convey to themselves and to others who they are now, how they came to be, and where they think their lives may be going in the future" (McAdams & McLean, 2013, p233).

Prominent researchers in this field includes Hollan and Wellenkamp (1994; 1996) who employed a psychocultural ethnographic approach to explore the personal experiences and psychological states of the Toraja people, a community of Indonesian wet-rice farmers. The researchers focused on various themes such as emotions, identity, interpersonal relationships, and mental states, including dreams and disturbances in consciousness. Throughout the interview, questions were not rigidly predefined but evolved from the themes that emerged during conversations.

Narrative techniques are central to exploring the self in waking and dreaming life. They allow participants to freely narrate their responses, providing a space to explore aspects of consciousness and experiences that might not be fully accessible through structured questioning. Furthermore, they allow individuals to negotiate personal experiences with broader societal contexts (McLean & Syed, 2015). However, there has been very little focus on using narrative techniques therapeutically and in research to explore how identity is experienced in dissociative disorders, let alone DPDR. Regarding DPDR, it is of question whether the sleep continuity hypothesis of DPDR symptoms extends to identity. Do people with DPDR experience their self as the same in waking and dreaming life? Are they able to retrieve a true sense of who their self was before the disorder in their dreams?

1.5.2.2 Defining Self

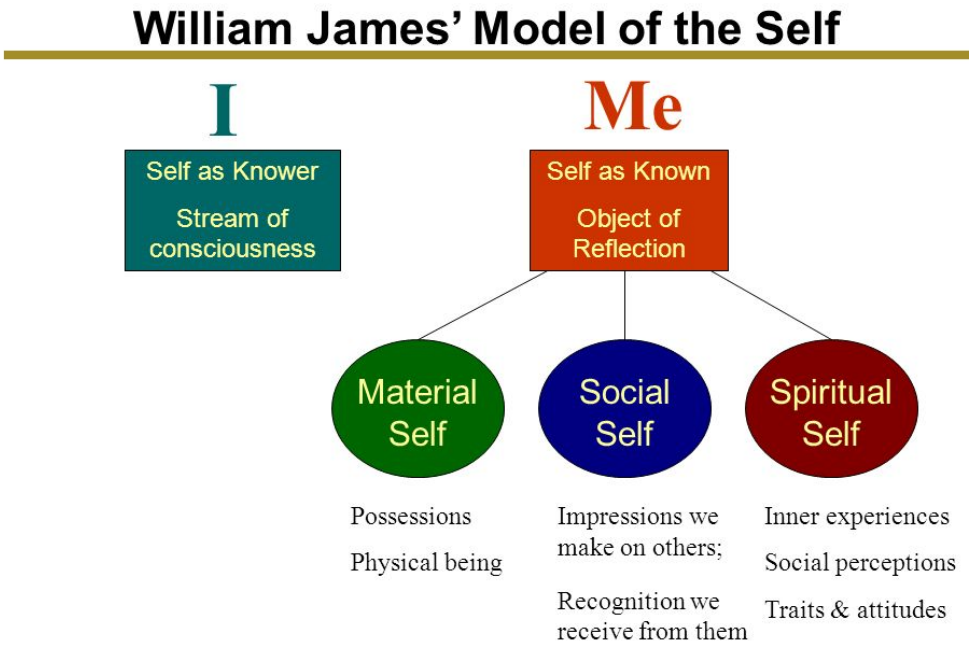
Not only is sense of self and identity central to dreams, but also to the aetiology of mental illness from which it is virtually impossible to separate (Thoits, 2013). It is therefore important to define the concept of 'self'; the heart of what this research hopes to explore.

The concept of the self as a fundamental entity has been central to debates across various disciplines over the years; evolving from ideas of the self as a fixed, core, stable entity across time and situations, to one that is dynamic, flexible and ever-changing depending on situational demands (Brown, 2017). One reason for the variation in theories, is that the notion of truth and authenticity in relation to theories of selfhood has depended on the philosophical tradition in which it is rooted.

A major shift in the concept identity as fixed occurred at the end of the 19th Century when philosopher James (1890) introduced a social aspect to identity. His model (figure 2) includes three aspects of self: 'material', 'social' and 'spiritual'. Neurobiological models such as that proposed by Qin et al. (2020) support James' view of the self as an integration of bodily and environmental signals, demonstrating distinct brain regions involved in processing these parts of the self.

Figure 2

James (1890) Model of The Self



Since James' (1890) model, identity theorists converge on the idea that self-representations can be cognitive and emotional, and expressed through words, images, neural patterns, or sensorimotor activities. They capture the self over time and encompass the actual self and potential versions of the self. Some of these representations are well-organised, containing extensive knowledge and rules for behaviour under certain conditions. Others are more fluid, created in the moment for specific social interactions. At any given time, only a selection of these representations is used to guide behaviour (Markus & Wurf, 1987). This idea of having multiple versions of oneself is known as the multiplicity of identity (Gara & Rosenberg, 1985).

It was not until after the 1980s that narrative concepts were used to understand identity (McAdams, 2018). Unlike other theories including those presented here which seek to definitively capture which traits or characteristics constitute identity, narrative theories emphasise the role of language, story-telling and episodic memory in creating a coherent and continuous self across time (Gallagher, 2000). A narrative identity is most broadly conceptualised as "the sense of self and identity that individuals reconstruct through narrating and reflecting on their own story, a continuously evolving subjective framework of self/others perceptions, personal agency, and social interactions" (Fino et al., 2024, p3). Capturing the complexity of the self from a narrative approach, Gallagher (2000) defined the self as "the sum total of its narratives, and includes within itself all of the equivocations, contradictions, struggles and hidden messages that find expression in personal life" adding "this view allows for conflict, moral indecision and self-deception" (p20). Thus, narrative theory makes the important contribution of time and sequencing to understanding the self and allows for a dynamic, flexible understanding of identity that captures the evolving nature of the person and their social context (McLean & Syed, 2015). The importance of narrative identity to DPDR was cited earlier, with Ciaunica et al. (2023) emphasising that one aspect of DPDR included

'*cognitive and narrative aspects'* (disconnection from one's personal stories, memories, thoughts and future plans).

Taking these various theories into consideration, Damasio (1999) writes that neuroscientists and philosophers can at best only offer informed speculation as to what the self actually is. Similarly, the theory of identity used by this research does not conform to one specific model, with all of them offering valuable conceptualisations. It is therefore informed by the literature above, and refers to the feelings, values, personal characteristics, physical experience, traits and attitudes held by a person at any given point in time, recognising this varies depending on social context. This aligns with a post-structuralist standpoint and with a narrative theory view that memory and story-telling may contribute to whether this identity is experienced as continuous or not. Finally, within this literature, the concepts 'self' and 'identity' are often used interchangeably. Thus, for the purpose of this research, these concepts are also used interchangeably.

Impairments in identity are termed in the literature as 'identity dysfunction' and are considered core to psychopathology (Nielsen & Wright, 2025). People experiencing identity dysfunction feel there is no 'me' or 'I' described in James' (1980) theory above that can be described or that exists in the world. Just as theories of identity vary, so too do those of identity dysfunction. Nielsen and Wright (2025) outline that disruptions in identity domains theoretically contribute to three main clinical manifestations of identity dysfunction: (1) disrupted phenomenological selfhood (incoherence, depersonalisation, emptiness, and the sense of having a 'false self'; (2) inconsistent attitudes and behaviour (sudden shifts in emotions, thoughts, and behaviour based on context; and (3) identity-related interpersonal problems (unstable attitudes toward oneself and other people, reliance on other people for a sense of self). All three of which were evidenced as experiences of people with DPDR in the literature review.

1.6 Rationale for the Current Study

Despite a long history of discussion around DPDR, there remains many gaps in knowledge. DPDR is characterised by disturbing symptoms that deeply affect one's sense of

self, yet few studies have delved into how these symptoms manifest in waking life and in dreams. While some qualitative research of people's experience of dissociation exists (Opsvik et al., 2022), the majority focusses on DID, and within that mainly on people's experiences of treatment (Boysen & Vanbergen, 2013). Due to the lack of understanding surrounding DPDR, there is a need for research to aid our understanding of symptoms from a first-hand perspective using qualitative methods to report such subjective phenomena (Ciaunica et al., 2023).

With the theoretical knowledge that dreams play an important role in consolidating and making sense of our identity, research which explores sense of self in waking life as well as dreams would contribute an understanding of how lived experiences confirm or disconfirm this theory. Additionally, research which assesses dream content may evolve our understanding of The Continuity Hypothesis by revealing specific symptoms experienced in both sleeping and waking states. Consequently, research linking sleep and dissociation may provide an alternative or supplementary explanation for the experience of such symptoms outside of the dominant trauma-focussed narrative, and thus promote exploration of interventions which normalise the entire sleep-wake experience (Van Der Kloet et al., 2012a) including how dreaming and dream contents are interpreted and handled by people with DPDR, and the impact of this when awake. This may help guide clinicians as to whether it could be therapeutic to use the dream world as a way to explore and re-connect with the "lost self".

1.6.1 Current Study Aims and Objectives

The aims of this study are to explore how sense of self/identity are experienced in waking life and in dreams of people with DPDR. Within this, to evaluate whether they are able to retrieve an authentic sense of self (before DPDR) in their dreams and what sense they make of this experience.

1.7 Systematic Literature Review

1.7.1 Introduction

The remainder of this chapter presents a systematic review and thematic synthesis of the qualitative literature exploring lived experiences of DPDR.

Due to the shifting terminology surrounding DPDR and its recent inclusion in the DSM-5 in 2013, there is a dearth of research into DPDR. Whilst a growing number of studies are exploring DPDR symptoms, these tend to report symptoms quantitatively. As described previously, other dissociative disorders or disorders which feature dissociative symptoms such as DID, schizophrenia and BPD are more established in the literature. Hence, qualitative studies exploring lived experiences of these disorders exist, with some focussing on sense of self and identity. However, qualitative research exploring lived experiences and impacts of DPDR symptoms is extremely limited and academic as well as clinical knowledge about the disorder are lacking.

To date, only one study has been published about identity in people with DPDR (Fino et al., 2024) and only one systematic review has been published about the lived experience of people with dissociative disorders and their identity, specifically their experience of multiplicity (Eve & Parry 2023). As the experience of multiplicity is not limited to DPDR, Eve and Parry (2023) included studies of other dissociative disorders and quantitative research. Of the 13 studies they reviewed, one was about people in the general population, two were on people with DPDR, three were on people with psychosis, and seven were on people with DID. The only findings related to the two studies on DPDR reported among the themes were the importance of having a positive support network and that feeling a different age to one's actual age contributed to a lack of congruence, both of which were only cited to come from Ciaunica et al.'s (2021) study. Their review therefore highlights the extreme lack of qualitative research about identity in people with DPDR.

Another type of research focussing on DPDR experiences are clinical case reports, though these are very limited, extremely brief and medically focussed, reporting mainly on medication treatment outcomes. They do not include qualitative insights from the person themselves. See for example Ghosh et al. (2007), Kethawath et al. (2021) and Mirjat et al. (2024).

Having qualitative studies of DPDR experiences would allow researchers to explore the nuances of how individuals perceive and navigate their symptoms, and has the potential to reveal hidden aspects of the disorder, such as the existential distress or identity struggles that individuals face, in addition to the impacts on coping, interpersonal relationships and daily functioning which may not be fully captured by standardised measures. Furthermore, qualitative studies may inform the development of more effective DPDR treatments and may speed up diagnostic processes. By understanding the subjective experiences and needs of people with DPDR, interventions can be tailored to address specific challenges and improve overall outcomes. For example, qualitative research may reveal the importance of psychoeducation, mindfulness techniques, or peer support in managing DPDR symptoms, leading to more holistic and person-centred treatment approaches.

Given the aims of this study, it was initially hoped the following literature review could explore the experiences of sense of self/identity in people with DPDR, however only one study has ever researched this (Fino et al., 2024). Thus, the aim was revised to review the current literature exploring the general lived experiences of people with DPDR. Currently, no systematic literature review has reviewed this topic area. The research question was:

1. What are the lived experiences of people with DPDR?

1.7.2 Method

1.7.2.1 Search Strategy

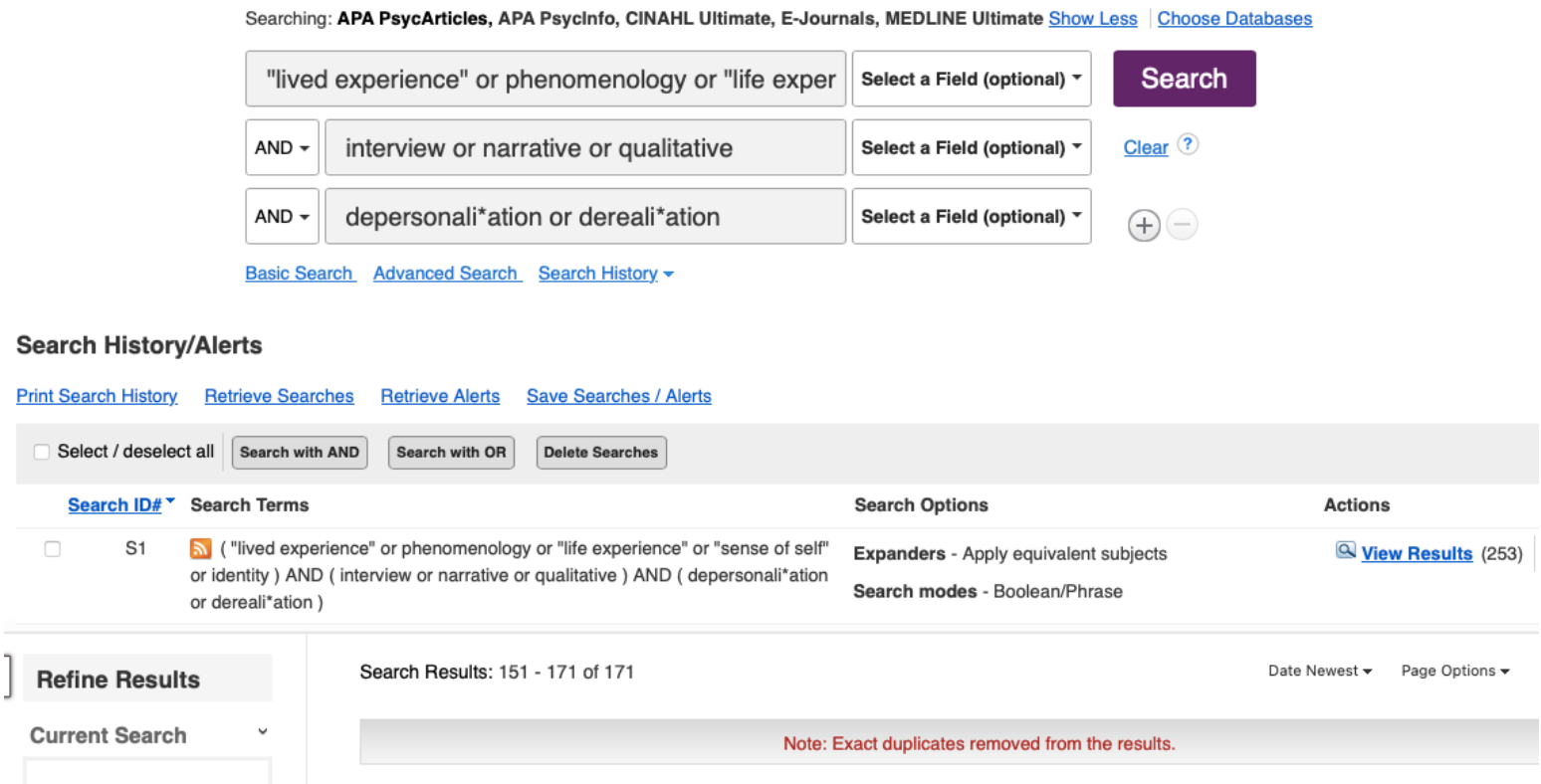
Five electronic databases were searched on the central database, Ebscohost in March 2024: **APA PsycArticles, APA PsycInfo, CINAHL Ultimate, E-Journals, MEDLINE Ultimate**. Search terms used were intentionally broad, so as not to exclude relevant articles. Search terms were set automatically to include title and abstract. The search terms used were:

("lived experience" or phenomenology or "life experience" or "sense of self" or identity) AND (interview or narrative or qualitative) AND (depersonali*ation or dereali*ation)

Figure 3 shows the results which this returned as of 18.04.2024. An alert was set at this time to notify the researcher if any publications subsequent to this date matched the search terms and additional papers from this are included in the prisma diagram to follow.

Figure 3

Ebscohost Search for Literature



1.7.2.2 Inclusion and Exclusion Criteria

Studies were included in the review if:

a) The methodology was qualitative

b) DPDR was the primary diagnosis/disorder being investigated

c) The study was a journal article or published thesis

Studies were excluded if:

a) The methodology was quantitative or used structured interviews.

b) The study came from a book chapter. An initial scan of book chapters found that qualitative excerpts were sometimes presented, however they did not form part of a research study and so did not follow a research question or methodology, therefore the quality of data could not be assessed. Furthermore, they did not provide sufficient quotes to be analysed.

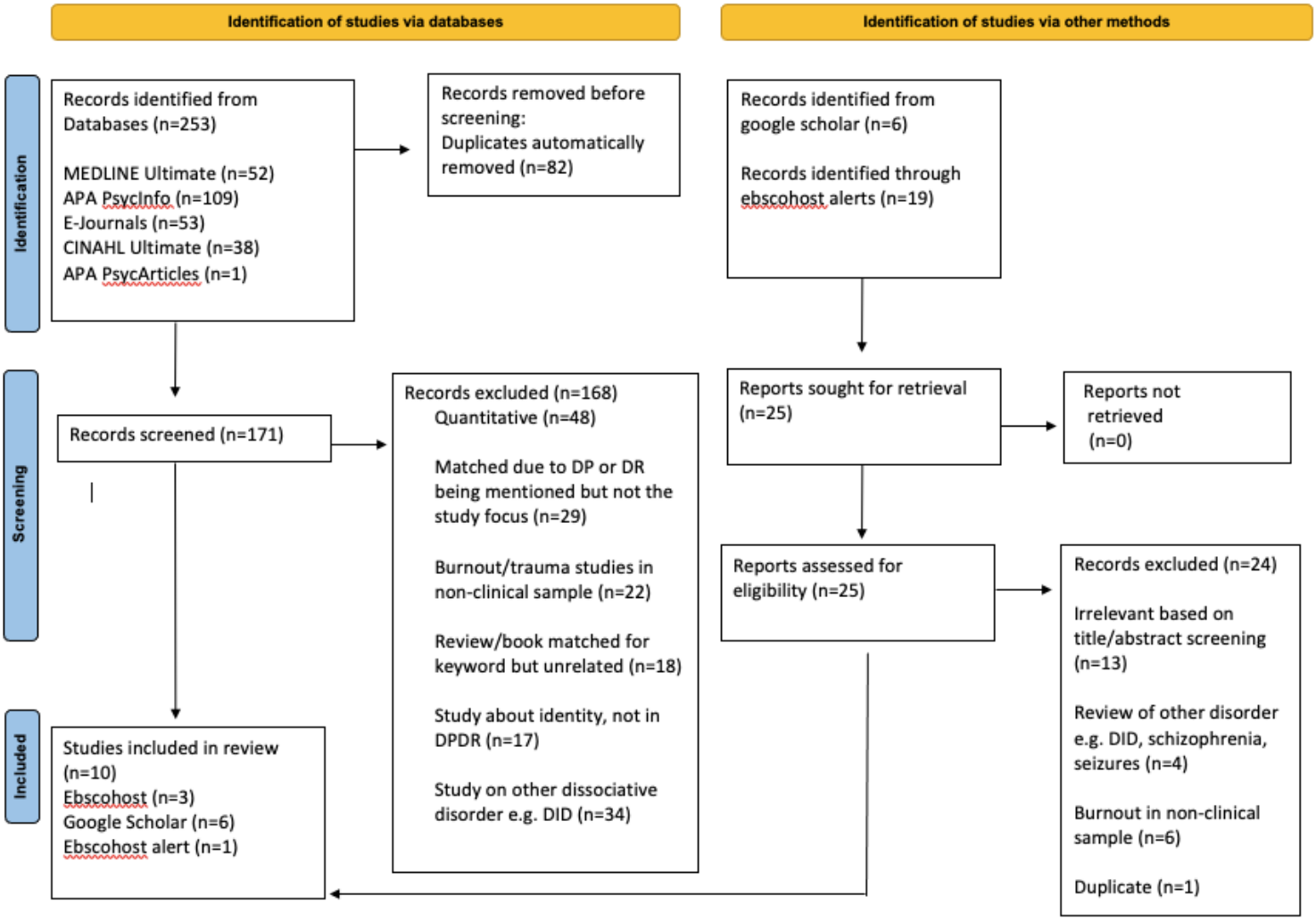
c) If DPDR was found in the results of a study but was not the primary disorder of the population being researched, e.g. studies about burnout. This is because of the presence of DPDR symptoms in other conditions such as schizophrenia, PTSD or DID which makes it hard to know how much of their symptoms are due to other mental health conditions. In these cases (where DPDR is only mentioned in the results but was not primarily investigated), the amount written about DPDR symptoms is insufficient to analyse, usually only one theme among many.

1.7.2.3 Screening Procedure

The Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines (Moher et al., 2009) were used for this review. Figure 4 below shows the literature search and screening procedure.

Figure 4

Prisma Diagram of Literature Search Strategy



It should be noted that one of the papers (Benjamin et al., 1998), included participants who experienced dissociation as measured using the SCID-D, therefore this could mean they had another dissociative disorder, other than DPDR. However, a decision was made to include this paper due to the lack of research available, as well as the fact that the vast majority of participants (89%) identified with symptoms of depersonalisation.

1.7.2.4 Quality Assessment

Assessing the quality of papers in a systematic review is imperative when deciding how appropriate a study is to answer the research question and provides context to the strength and credibility of conclusions drawn by the synthesised findings (Noyes et al., 2018). With a rise in qualitative healthcare-related studies, Hannes et al. (2010) discuss that quantitative measures of quality such as The Cochrane Collaboration's 'Risk of bias' tool are no longer applicable, and specific tools for qualitative research should be used.

When synthesising qualitative health-related evidence, the Critical Appraisal Skills Programme (CASP, 2018) tool is most commonly used to appraise the quality of studies and is therefore used in this review. This tool is endorsed by the Cochrane Qualitative and Implementation Methods Group (Long et al., 2020). It includes a checklist of 10 questions seeking to explore the validity and value of study results. However, unlike quantitative quality assessment tools, there is no scoring system which means that author discretion is required. Full details of the CASP (2018) quality assessment can be seen in Table 1 below.

With the exception of one study (Haft, 2015), the CASP tool revealed the rigour of studies included in this review was high, particularly for the type of methodology and analysis used. All studies clearly stated their aims and justified the method of data collection and qualitative analysis well. Research designs were appropriate for achieving the aim of providing an in-depth understanding of DPDR lived experiences.

The methods for obtaining qualitative information varied, with some citing the use of semi-structured interviews (Dong, 2023; Fino et al., 2024; Pietkiewicz et al., 2023), though these studies did not publish examples of interview questions, therefore how open-ended or leading they may have been is unknown. Others used validated tools, all of which seemed to allow participants to freely provide context about their experiences. For example, Pienkos and Sass (2022) used The Examination of Anomalous Self Experience (EASE) and Examination

of Anomalous World Experience (EAWE); Ciaunica et al. (2023) used the EAWE-self report version and The Inventory of Psychotic-like Anomalous Self-Experiences (IPASE); and Benjamin et al. (1998) used the SCID-D and The Subjective Experience of Parenting Scale (SEPS).

While the IPASE contains closed questions which are rated on a Likert scale and quantified, this was used in conjunction with the EASE and EAWE which are effective at eliciting rich, nuanced descriptions of experience (Ciaunica et al., 2023). The SCID-D, discussed previously, also contains space for follow-up questions. Finally, Benjamin et al. (1998) provided numerous examples of open-ended questions used such as "What do you believe most gets in the way of your parenting?" and the follow-up interviews were described as a space for participants to provide a "narrative" of their experience of answering the SCID-D on their parenting experiences.

Ethical issues were largely taken into consideration, such as participants being allowed to terminate an interview should they become distressed, and anonymisation of transcripts. However, three papers did not provide rigorous data analysis (Fury, 2023; Haft, 2015; Williams, 2022). All studies ended their results or discussion sections with a clear statement of findings which answered the research aim, although Watson (2022) stated their conclusions less clearly. All papers made suggestions for future research, although in the case of Haft (2015) this was limited to one sentence. Three papers discussed the clinical implications of their results (Fury, 2023; Benjamin et al., 1998; Pienkos & Sass, 2022), while all papers discussed how their findings expand on the understanding and knowledge of DPDR experiences.

All studies clearly explained their method of recruitment, and used standardised measures to determine symptom severity, or recruited people with a formal diagnosis (Pienkos & Sass, 2022). However, Ciaunica et al. (2023) noted their participants may have had comorbid

mental health conditions which were not screened for and which could have influenced their symptoms. Two studies were autoethnographies of the authors' personal experiences of DPDR (Watson, 2022; Williams, 2022).

Table 1
Quality Appraisal of Included Studies (CASP, 2018)

Author	Clear Statement of Aims	Qualitative Methodology Appropriate	Research Design Appropriate	Recruitment Strategy Appropriate	Data Collection Appropriate	Researcher-Participant Relationship Considered	Ethical Issues Considered	Rigorous Data Analysis	Clear Statement of Findings	Research Value
Pietkiewicz et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Discussed limitations, future research, implications
Watson (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Discussed future research but no clear questions for this
Ciaunica et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Discussed generalisability and future research
Pienkos & Sass (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Discussed future research, generalisability, relevance to clinical practice and implications
Benjamin et al. (1998)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Discussed clinical implications and recommendations for treatment
Haft (2015)	No	No	No	Unclear	Unclear	No	No	No	Yes	One sentence regarding future research

Dong (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Summary of how the study adds to understanding of this population. No consideration of future research, limitations, generalisability or implications.
Fury (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Discussed future research, generalisability, relevance to clinical practice and implications
Williams (2022)	Yes	No	No	Yes	Yes	Yes	Yes	No	Yes	Discussed future research
Fino et al. (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	First study exploring impact of DPDR on identity and coping. Use of narrative approach.

1.7.2.5 Data Synthesis

This review followed the thematic synthesis framework developed by Thomas and Harden (2008) who recognise the frameworks similarity to other qualitative synthesis methods such as meta-ethnography. However, they describe a 'clear separation' between these methods, with meta-ethnographies being viewed as 'data-driven', compared to their method which they argue is 'theory-driven', as having a review question provides a theoretical structure which makes it possible to develop higher order thematic categories which go beyond describing the study content. Therefore, where there is a specific review question to be answered, a thematic synthesis would be more appropriate compared to a meta-ethnography which is more suitable when a body of literature is being explored in and of itself, where the review questions are broader, or emerge during analysis (Thomas & Harden, 2008).

Thematic synthesis was developed to avoid bias of the research process and of the primary research being reviewed and involves three stages: 'line-by-line' coding of text; developing 'descriptive themes'; and generating 'analytical themes'. In stage one, all text labelled as 'results' or 'findings' were extracted, including verbatim quotes from participants. Each article was read multiple times to gain familiarity with the data. Each line was coded, with every sentence having at least one code applied. In stage two, the researcher looked for similarities and differences between the codes to group them into a meaningful structure of descriptive themes. In the final stage, analytical themes were developed, whereby insights into the key messages and meaning of the data were inferred to answer the aims of the systematic literature review.

1.7.3 Results

Ten studies met the inclusion criteria. Characteristics of these included studies are shown below in Table 2.

Table 2
Characteristics of Included Studies.

Author	Country of study	Participant ethnicity	Sample size	Age	Gender	Aims	Data collection	Method of analysis	Themes
Watson (2022)	USA	n/a	1	n/a	Female	Explore the ways communication surrounding DDD anchors and alleviates the disembodiment that accompanies DDD experiences	Autoethnography	Narrative	1. Diagnosis: life stressors 2. Coming to terms: sharing information about diagnosis, learning about the disorder, therapy, difficulty accepting lack of control, crafting normalcy. 3. Life with DDD: managing societal stigma managing, being open with others
Ciaunica et al. (2023)	n/a	11 White, 4 East Asian, 1 Black, 8 South, West or Central Asian	24	Mean 23	18 female, 6 male	Provide in-depth examination of self-reported disturbances of one's relatedness to one's self and the world	Semi-structured interviews using Inventory of Psychotic-like Anomalous Self-Experiences (IPASE); Examination of Anomalous World Experience-Self Report version (EAWE-SR)	Inductive thematic analysis	1. Detachment 2. Embodiment 3. Identity Changes 4. Idiosyncratic Beliefs 5. Affective Changes 6. Change in communication and approach to language 7. Anomalous reactions to others 8. Difficulty relating to others 9. Social anxiety and self-scrutiny 10. Unusual experiences of time 11. Changes in perception and sensation 12. Confusion of the boundaries between self and world 13. Disturbances of attention and cognitive organization 14. Greater existential concerns about others and the world

Author	Country of study	Participant ethnicity	Sample size	Age	Gender	Aims	Data collection	Method of analysis	Themes
Pienkos & Sass (2022)	USA	n/a	4	20s-50s (mean 33)	Male	Identify qualitative features of experiences and how they relate to experiential core or characteristic Gestalt of the disorder. Clarify differences in experiences with schizophrenia	Semi-structured phenomenological interviews using the Examination of Anomalous Self Experience (EASE); Examination of Anomalous World Experience (EAWE)	Descriptive phenomenological analysis (Giorgi, 2009)	1. Loss of resonance 2. Detachment from experience 3. Loss of self 4. Commitment to reality
Benjamin et al. (1998)	USA	49 Caucasian, 4 Black, and 1 Native American.	54 (7 interviews)	Mean age 35	Female	Create richer understanding of the nature/ structure of the problems of mothers with dissociative disorders	Structured Clinical Interview for Dissociative Disorders (SCID-D); Subjective Experience of Parenting Scale (SEPS) open-ended questionnaire; Post-study interview.	Not stated	1. Amnesia – impact on ability to care for children, impact on confidence 2. Depersonalization – Feeling disconnected from children 3. Derealization – Not recognising loved ones 4. Identity confusion – Forgetting their role as a mother, impact on daily functioning, difficulty setting boundaries 5. Identity alteration – emotions taking over identity and behaviours. Reverting to childlike behaviours 6. Mothers' assessments of what interfered with their parenting

Author	Country of study	Participant ethnicity	Sample size	Age	Gender	Aims	Data collection	Method of analysis	Themes
Haft (2015)	n/a	n/a	1	n/a	Female	Not stated	Clinical Vignette. Case discussion from psychoanalytic sessions with author	None stated	1. Treatment and relationship to therapist 2. The Search for Psychic Cohesion in Social Support 3. Development of transference
Dong (2023)	Cameroon	n/a	3	22-24	2 female, 1 male	Decipher how DPDR is experienced in people with sickle cell disease	Semi-structured interviews	Content analysis	1. Sensations of modified body and being outside of one's own body 2. Feelings of transformation into another than oneself, duplication, imminent psychic annihilation and detachment 3. Feelings of derealization, alteration of reality, strangeness of the outside world and going in circles 4. Emotional indifference and physical numbness 5. Anxiety and obsessive concerns 6. Circumstances of the appearance of DPDR at interview: the role played by the disease and the developmental period

Author	Country of study	Participant ethnicity	Sample size	Age	Gender	Aims	Data collection	Method of analysis	Themes
Fury (2023)	USA	n/a	>1000	n/a	n/a	To gain insight into the lived experiences of people writing about DP	Subreddit posts between April 2021-22 on topics: 'dissociation', 'depersonalization' and 'dpdr'	Thematic analysis guided by interpretative phenomenological analysis (IPA)	1. Identifying anxiety as the basis of DP 2. Living with DP – emotional impact of coming to terms with diagnosis, effects on school and work 3. No one in IRL Understands 4. Feeling desperate to the point of considering suicide 5. Personal Description of a Symptom or State
Williams (2022)	USA	n/a	1	n/a	Female	Explore themes, motifs, and symbols found in the artwork of an individual with DPD and how this connects to their lived experience of suffering from DPD	Reflective journaling using art work from the author themselves created pre and post-diagnosis of DPD, as well as art created at the time of this study.	Dr Betensky's phenomenological approach to art therapy (1995).	1. Colour – yellow and orange (hope, safety, and warmth), and red (anger and frustration) 2. Numbers – interpretation of this as signifying a narrative, separating from parents, commencement of a heroic journey 3. The eye – looking away or covering eyes. 4. The hand 5. "Nothing Body" as a Cracked Eggshell

Author	Country of study	Participant ethnicity	Sample size	Age	Gender	Aims	Data collection	Method of analysis	Themes
Pietkiewicz et al. (2023)	Poland	n/a	8	24-37	Female	Explore DPDR in healthcare professionals who participate in resuscitation actions which involve patient death	Semi-structured interviews	Interpretative phenomenological analysis (IPA)	1. Getting excited and alert before rescue operations 2. Running on autopilot under stress 3. Filtering out stimuli to avoid distraction 4. Agitation affects the perception of time 5. Abreactions when detachment fades 6. Selective memory about the course of events 7. Dealing with loss
Fino et al. (2024)	UK	13 UK residents, and 6 residents in 'other countries'	19	19-50, (mean 31)	6 female, 4 male, 4 prefer not to say	Explore adaptations to DPDR and narrative identity reconstructions, e.g. whether/how DPDR affects their sense of who they are, beliefs in capacity to influence own life and relationships with others.	Online interviews 'based on a semi-structured protocol that required participants to engage with storytelling on targeted aspects of their lived experience of DPDR'	Mixed inductive/ deductive thematic analysis	1. DPDR onset as a major life turning point and contaminator 2. Meaning-making, exploratory narratives associated with the lived experience of DPDR 3. Coping strategies, tentative redemptions, and failed resolutions. 4. DPDR, Disrupted Agency, and Communion

Note: Depersonalisation-Derealisation Disorder (DDD), DPD (depersonalisation disorder), DP (depersonalisation), IRL (in real life)

The process of thematic synthesis generated five themes, cross-tabulated in table 3 to visually represent the studies from which they are derived.

Table 3

Cross-Comparison of Studies by Concept

	Sensory	**Identity**	**Interpersonal**	**Affective**	**Daily Functioning**
Watson (2022)	X		X	X	
Ciaunica et al. (2023)	X	X	X	X	X
Pienkos & Sass (2022)	X	X	X	X	
Dong (2023)	X	X		X	
Haft (2015)	X	X	X	X	
Williams (2022)		X		X	
Fury (2023)	X	X	X	X	X
Pietkiewicz et al. (2023)	X			X	
Benjamin et al. (1998)		X	X	X	X
Fino et al. (2024)		X	X	X	X

Struggling to Navigate Distortions in Time and Sensory Perception

One of the most common themes found across seven studies was distortions to sensory experiences. Distortions in perception of time was most common, causing confusion about whether things are being perceived, imagined or remembered (Ciaunica et al. 2023). For example, participants in Ciaunica et al.'s study (2023) expressed changes to both implicit time (how time is experienced in the moment) and explicit time (how we reflect on our past or likely future). Some participants were unable to integrate ideas about their past or future and could only focus on the present. They described feeling as though the future might not happen, that it was irrelevant or that it did not relate to their actions in the present. Similarly, interviews by Pienkos and Sass (2022) revealed how difficulties integrating the past and future impacted on people's sense of continuity of themselves; feeling that past events had not actually happened to them, or that they will not exist in the future. Other distortions included feeling time had stopped or disappeared or moved faster than usual, also noted by participants in Pietkiewicz et al.'s (2023) study. These participants were paramedics and their experiences of DPDR were transient, rather than chronic as was the case for participants in the other studies. Nonetheless, they experienced time as moving much faster than reality, saying that during emergency tasks, two hours felt like five minutes, although this returned to normal after the task was over.

Not only did changes to time perception impact people's memory and conceptions of the past and future, but it warped people's perception of their own bodily movements, which was confusing and disorienting: "*I couldn't tell if I was dreaming or I was going mentally insane. I woke up to seeing my surroundings and body move as if it was on fast forward. My hands were moving as if I was putting a video on high speed to skip to a scene. I felt dizzy, seeing everything move as if time had drastically sped up felt like I had left my body and was watching it as if it were a video*" (Fury, 2023).

Several participants across studies noted distortions to vision and sound. For example, images on screen appearing too small, far away or too close (Watson, 2022). Difficulty focussing vision, temporary or partial blindness, and blurry vision were also reported (Ciaunica et al., 2023; Watson, 2022). Some noted they could perceive sounds or images that were not actually there (Ciaunica et al., 2023) while others described difficulty identifying the direction or location of its origin or experiencing sensitivity to background noises (Ciaunica et al., 2023). This study also expanded on how such distortions impacted people's ability to perceive objects, for example shapes, colour, and sizes of objects changed, and some textures felt different, making it difficult to perceive objects as a whole; something participants in Pienkos and Sass's (2022) study also explained, due to focussing on individual elements instead.

Not only were people's senses distorted, but many reported loss of sensitivity to sensations (Pienkos & Sass, 2022), or disconnection from their senses altogether. This related to the intensity of touch and vision, with things feeling "less vivid, distant, duller, less crisp" or lacking in vibrancy and depth, as though there was a film or screen between the person and the world (Ciaunica et al., 2023). Watson's study (2022) described: "*When I touch any part of my body it feels weird it's like I'm disconnected to my senses it's hard to describe…Also when I swallow I can't feel anything*". This feeling of disconnect even extended to how people felt about themselves, with people describing a sense of "inner emptiness": "*I always feel as if my body is empty, as if I had no strength*", "*my head is as if it were empty*" (Dong, 2023). Such feelings of emptiness and sensory distortions led people to question reality, sometimes feeling defeated: "*Nothing has meaning*", "*Like sometimes it just feels like my head is full of TV static*" (Fury, 2023). However, while most people were left questioning their reality, some did not question the factual reality of the world around them, and instead expressed a strong desire and commitment to experiencing reality as they did before DPDR (Pienkos & Sass, 2022).

I Miss My Old Self: Changes in Identity, Roles and Beliefs

Across eight studies, participants consistently described profound disruptions in their sense of self caused by changes to the way they thought, felt and behaved compared to before DPDR.

Williams' (2022) artwork depicting her own struggles with DPDR heavily featured pictures of eyes often being covered which she interpreted as symbolising her struggle with her sense of self. Fury (2023) and Pienkos and Sass (2022) highlighted feelings of detachment and emptiness, with participants experiencing a sense of loss or transformation in their identity. This was described as a feeling of death or loss of their old self, and no "new" self to replace this loss, but rather an "emptiness" "nothingness", "vacuum" (Fury, 2023), or "self-less state" (Pienkos & Sass, 2022). Such descriptions seem related to the dulled-down sensory experiences some people described in theme one. Regarding sense of self, some people expressed feeling as if there is no self with whom this unfamiliar world *can* resonate, along with a diminished sense that their own experiences are truly or fully happening *to them* (Pienkos & Sass, 2022).

While some habitual ways of behaving remained familiar, these were described as "hollow" and lacking any accompanying feeling (Pienkos & Sass, 2022). These feelings of disconnect from their former selves related to a distorted sense of time, noted in the previous theme, with participants sometimes feeling significantly older or younger than they did prior to their diagnosis (Ciaunica et al., 2023). More commonly however, the disconnect from their former self was caused by changes to the way they now thought and behaved. They described feeling their thoughts were not coming from themselves, but were being controlled by someone else (Dong, 2023; Haft, 2015; Pienkos & Sass, 2022), having fewer or slower thoughts, difficulty accessing their thoughts, or not having any thoughts at all (Pienkos & Sass, 2022). This experience caused a general feeling of not being fully present to oneself, of feeling like

an observer of oneself or the world, or of being detached from or not a part of the world (Ciaunica et al., 2023).

Ciaunica et al. (2023) found some individuals experienced conflicts between their thoughts and actions, describing a disconnect between their "thinking-self" and "speaking-self". Pienkos and Sass (2022) further noted participants sometimes felt detached from their own speech, as if words emerged automatically without a clear link to their thoughts or a sense of control over their expression. Similarly, Haft (2015) reported on a patient whose hand movements felt externally controlled rather than self-directed. As well as changes to the frequency and amount of thoughts people had, the content of people's thoughts changed following the onset of DPDR, which may help explain why some people described the notion that their thoughts were coming "from someone else". These thoughts related to attitudes, beliefs and values regarding their relationships, society, humankind, existence and reality itself. For example, "*I feel like a different person daily…My perspective on the world shifts to the point I genuinely feel different. My view on people also changes which kinda freaks me out*" (Fury, 2023). Ciaunica et al. (2023) expanded on this with other examples including: feeling indifferent to the suffering of others, feeling guided or predestined in life, that events conveyed a special meaning to them, that the worlds end was imminent, or forming beliefs without apparently sufficient supporting evidence.

While many studies focussed on changes to peoples thoughts, Benjamin et al. (1998) highlighted profound differences in the way mothers with DPDR behaved, which seemed out of their control and impacted their ability to function and parent their children. Mothers stated they would become "automatically and abruptly become rageful or childlike" and felt compelled to act on the part of their "alters" which was "in charge" in that moment, regardless of the outcome. As a result, their children were left confused and angry, friends and family were needed to support child-care, and mothers were left feeling confused as to their role as a

mother and low in self-esteem: "*I isolate from my child. My confusion confuses her. I ask 'Who am I?' 'Who is she?"'* ; "*I get so confused that I have an imaginary space. Leave me alone. I can't figure things out. I keep them [the children] away*." These descriptions mirror the feelings described in other studies including feeling "*as if I didn't belong to myself...*" (Dong, 2023).

Inter-Personal Difficulties: Navigating Societal Stigma and Altered Relationships

Seven studies included descriptions about sense of connectivity to others having changed as a result of DPDR. This theme highlights the ways people's relationships altered due to: navigating societal stigma, difficulty relating to others emotionally, or feeling uncomfortable in social situations.

In Watson's (2022) personal account of developing DPDR she wrote "*Conversations around mental disorders can often be uncomfortable...I find that when I use sarcasm or dark humor to navigate the topic, I see a visible sigh of relief from my conversation partner*". Watson's study provides a positive example of interactions with others, as she noticed that because little is known about DPDR, other people have fewer preconceived notions about her condition, which provided her with a sense of agency in telling her story and alleviated the sense of disembodiment she felt. In stark contrast, Fury's (2023) study highlighted many people felt frustrated others did not know about or understand DPDR. This left them feeling hopeless due to people not being able to relate to their experiences: "*Every time I talk to someone about it they say "Oh, I had brain fog too, I understand*"". Not only did this cause frustration socially, but medically treatment was widely unavailable because it was not recognised in certain countries [not specified]: "*There's no such thing as DP or DR in my country. Doctors either treat it like Schizotypal disorder or even doesn't know about this disease. They may recommend you some drugs or medications referenced to epilepsy but nothing else. Which means there's also no therapy or special treatment for this disease*".

The reasons people felt disconnected from others varied from a general feeling of not belonging (Haft, 2015) to obstacles in knowing how to act socially. Participants in Ciaunica et al.'s (2023) study described high levels of social anxiety and self-scrutiny, which exacerbated feelings of self-doubt, fear and self-criticism in social situations. For example, not knowing how to respond or how much eye contact to make. They therefore struggled to relate to others, who they felt judged them heavily, which fuelled feelings of social isolation. The mothers in Benjamin et al.'s (1998) study also felt disconnected from others, specifically their children, however they perceived this to be due to exhaustion and feeling overwhelmed. Many mothers described feeling "absent" or "out of touch", unable to hear their children in depersonalised states. Participants in these studies and in Fury's (2023) study spoke about being unable to recognise loved ones or people once familiar which was exhausting and anxiety-provoking. To mitigate this, Fino et al. (2024) discussed the importance of validation and non-judgemental acceptance from family and friends which helped reinstate a sense of agency and hope for the future.

There were differences in ability to emotionally connect with others. Some felt a loss in their ability to do so (Dong, 2023; Pienkos & Sass, 2022) or even indifferent to others' pain and suffering (Dong, 2023). Conversely, Watson (2022) described feeling more connected to others as a result of her diagnosis, and felt her experiences led her to be more empathetic towards others with mental health difficulties. As a lecturer, she said her students likewise sought her out to open up about their struggles following her own disclosure. Ciaunica et al. (2023) found some people felt stronger concern, empathy and responsibility toward others, the world and humanity as a whole after DPDR, and in contrast to the experiences above, felt especially close to or familiar with people who they were in fact *unfamiliar* with.

Negative Affective Responses

As discussed, many felt a lack of connection to others, emotionally and socially, and sensory changes led some to feel a loss of connection to the world around them. This theme expands on the impacts of these changes discussed in all ten studies. Impacts were mainly negative, varying from low mood, anxiety, hopelessness, suicidality to indifference.

One of the most commonly mentioned emotional responses to DPDR symptoms was anxiety (Ciaunica et al., 2023; Dong, 2023; Fino et al., 2024; Fury, 2023; Haft, 2015; Pienkos & Sass, 2022; Pietkiewicz et al., 2023). Reasons for feeling anxious varied; trying to "get away" from the disorder (Haft, 2015), worrying that "things are always happening" to them outside of their control and trying to figure out why (Dong, 2023; Fino et al., 2024; Fury, 2023), not knowing how to cope with situational demands or how to respond in social situations (Pienkos & Sass, 2022), or for "no apparent reason" (Ciaunica et al., 2023). Fury (2023) and Watson (2022) both highlighted the link between anxiety and DPDR symptoms, as experiencing anxiety seemed to precede or worsen symptoms. Both studies reference anxiety about COVID-19*: "I was doing good but then my anxiety shot up because of COVID scare and now I am constantly anxious which is causing me to depersonalize"* (Fury, 2023). For many, anxiety was said to be pervasive and overshadowed all experiences rather than being directed towards specific objects, people or events (Pienkos & Sass, 2022). As the only study to interview people with transient DPDR, Pietkiewicz et al. (2023) found ambulance workers became anxious after having experienced a state of DPDR, as they came to realise their true surroundings and become aware of their bodily fatigue and what they had just experienced. People's reactions to experiencing enduring states of anxiety also varied, with some becoming more distressed at the realisation of the severity and longevity of these changes, while others described a certain acceptance of their experience or even appreciation of some of the insights it could bring them (Pienkos & Sass, 2022).

The next most common reaction was indifference or numbness, noted by four studies (Ciaunica et al., 2023; Dong, 2023; Pienkos & Sass, 2022; Williams, 2022), which seemed a consequence of the loss of sensory and social connection to others and the world. Some described their words and actions felt meaningless or fake (Pienkos & Sass, 2022). For those who experienced dulled senses, nothing stood out to them, captured their attention or made them feel excited, leading to feelings of passivity or never being fully engaged, with everything seeming equally distant, vague, unremarkable or useless (Ciaunica et al. 2023; Pienkos & Sass, 2022). A participant in Dong's (2023) study discussed feeling unable to feel love for anyone but one person: "*I strive but I feel nothing. It bothers me because I see myself as a hypocrite…What if I wasn't made to love?*"". Unlike the people who primarily felt anxious, this reduced anxiety, due to a lack of concern about the outcomes of their actions, which one might hypothesise could extend to social situations which many noted as anxiety-provoking. Williams (2022) described herself as a "nothing body" several times throughout her artwork. Comparing herself to an eggshell, she wrote "*It felt like even if the body smashed itself open like an eggshell, it wouldn't feel like "something"; it would still be nothing. I expressed that I could see myself trapped in the body, but I could not see myself escaping*". This quote implies a sense of hopelessness that things cannot change. This sense of demoralisation was mentioned in one other study, Ciaunica et al. (2023), as participants felt there was no worth trying to achieve their goals, as nothing was in their control. Doing so would be meaningless and tiring.

Other studies revealed feeling hopeless or despair at not being able to change or rid DPDR symptoms led some people to feel low or suicidal (Benjamin et al., 1998). For participants in Fino et al.'s study (2024), this was due to the internalised-stigma of being unable to establish an identity beyond being someone with DPDR. Fury (2023) compiled several internet threads of people who echoed feeling low or suicidal. Many entries admitted contemplating suicide daily, feeling unable to continue exerting effort to understand and

overcome their symptoms. Many feared they would never feel normal again and this was compounded by the lack of known therapeutic treatment options. Others felt they held no value as a person anymore. One person contemplated ending their life due to existential questions which their experiences sparked, wondering "*What if death isn't actually death, what if it's actually a doorway to a new/real reality? what if what lies beyond death is a sort of 'heaven', and dying sooner means you get there sooner?"*.

Challenges to Daily Functioning

This final theme elaborates on how the difficulties discussed in the previous themes posed challenges to people's daily functioning, including tasks they used to be able to do and depend on being able to do. Four studies are included in this theme (Ciaunica et al. 2023; Fino et al., 2024; Fury, 2023; Benjamin et al. 1998). While the areas of people's lives impacted varied – from difficulty performing in academic or work environments, caring for children and performing daily living skills – a running theme was that this loss of function was caused primarily by memory difficulties.

Multiple people in Fury's (2023) study said they left or were forced to leave university, high school, or their jobs due to difficulty concentrating or focussing which led them to "zone out" and make mistakes or stopped them from learning new information. For many, the change seemed sudden, with some recounting being "straight A students" or holding scholarships prior to DPDR. This sudden change in ability left people feeling confused and at a loss as to how things might return to how they were: "*I can't take my mind off of it and every time I try and distract myself I lose my ability to think logically and forget everything…I don't know how I'll ever go back to normal*". Others felt panicked, which stopped them from doing things they used to enjoy: "*Anxiety and depersonalization/derealization has changed my everyday life and the things I once loved to do. I'm constantly afraid. I sometimes can't even shower normally*

because I feel a sudden impending doom caused by this mental disorder". While these quotes exemplify how distraction heightened their anxiety, participants Fino et al.'s study (2024) found routine tasks such as tidying or cooking helped them achieve a balance between internal and external awareness, which they perceived as "normal" and provided temporary alleviation from their symptoms.

Similarly to Fury (2023), Ciaunica et al. (2023) noted disturbances in people's attention and cognitive organisation skills, resulting in difficulties including not noticing things that are obvious to others or becoming distracted by irrelevant details or their own thoughts. Others felt unable to effectively make decisions because they felt overwhelmed. Though participants in this study did not mention being unable to work or study, the content of their experiences resonated strongly with those described above. For example, participants described changes to their ability to communicate effectively, problems with finding the right word or clearly articulating themselves, lacking emotional intonation in speech or feeling unable to organise their thoughts effectively into speech. They also described various difficulties understanding speech or written language, which one may assume would impact their ability to work and study. As well as communication difficulties, some described difficulty moving their body, which left them unable to perform daily living activities.

Mothers interviewed in Benjamin et al.'s (1998) explained the impact of DPDR on caring for their children. A common theme was a loss of memory, likened to amnesia, for example, forgetting information they had given their children, forgetting to pick their children up from school, or forgetting to give them medications. One mother said "*Sometimes I forget that I'm her mother"*. Another said her memory problems stopped her from protecting her child because she was not emotionally available when her daughter was being sexually abused by her step-father. Mothers in this study described a sense of being "absent" or "out of touch" with their children, sometimes even unable to hear them; a passive state described in the

previous themes. Yet this seemed to be a state which many fluctuated in and out of, with some saying they had to stop what they were doing when they felt a depersonalised state come on. The unpredictability of when this would happen led many to become rigid and guarded in their parenting approach, due to feeling uneasy and need to protect their children. It was often said children had to care for their mothers in times when they could not remember what they should to be doing.

1.7.4 Discussion

This literature review provides a thematic synthesis of ten qualitative studies of lived experience of DPDR. Five themes highlighted that the most prominent and common experiences were changes to people's: a) sensory perception, b) sense of self and identity, c) ability to connect with others, d) affect, and e) daily functioning.

The findings showed that negative impacts on mood was most commonly reported, featuring in all studies. Within this, there was variation as to whether people were anxious, low, suicidal, hopeless or indifferent to their symptoms and its impact. It was highly reported that people struggled with distortions to senses including touch, sight, sound and time-perception. Equally discussed was the impact on people's sense of self, identity or role. While this was initially hoped to be the focus of the literature review, there was not enough material to report on this alone, as it was not the focus of the original studies. Nonetheless, this review found that a common cause of confusion about identity was a change in the way people thought and behaved, and incongruence between the two, compared to before the onset of DPDR. This included core beliefs about others and the world. Finally, studies expanded on the impact of DPDR symptoms on daily functioning including providing childcare, working and studying. These findings add to the understanding of the impact of DPDR, which are most widely reported clinically and in the literature using semi-structured interviews. The themes support

those which are featured on such tools, whilst adding context to the situations in which they arise and the emotional impact on the participants of the research and people around them.

Despite these contributions, there are several methodological limitations. Firstly, including more papers would have strengthened the methodological rigour of this review. However, the number of papers included underscores the lack of qualitative research on people living with DPDR. Secondly, due to the dearth of research available, studies from all countries were included. Although the papers shared many commonalities, it is important to recognise that experiences relating to interpersonal difficulties, stigmatisation and availability of treatment will be influenced by systemic factors including cultural beliefs and the understanding or availability of treatment in that country, as they follow differing mental health policies and procedures. Thus, the experiences in this review cannot be generalised as representative of the UK or NHS.

Thomas and Harden (2008) draw attention to the limitations of synthesising qualitative research, one being that findings are dependent on the judgement and insights of the researcher. They suggest any method of qualitative synthesis poses the risk of de-contextualising original findings and wrongly assuming these are commensurable. In this review, subjective interpretations were necessary to draw comparisons among studies. For example, it was postulated that perhaps the memory and concentration difficulties reported in the study by Ciaunica et al. (2023) could have impacted participants' ability to work or study, though such impacts were not explicitly made by the participants themselves.

Further research is needed to corroborate the current findings and further qualitative research is needed to explore the lived experiences of people with DPDR, specifically in the UK. Currently, no research has explored people's experience of their sense of self, and how this is experienced in waking life compared to dreams, thus leading to the rationale for the current research.

Methodology

2.1 Chapter Summary

This chapter provides an account of the methods used. First, the motivation for this thesis and participant pool stem from a previous study which took place in 2021. An overview of this study is explained first, before describing the procedures and ethical considerations of the current study.

Within the design, an overview of qualitative and quantitative methodologies is provided and the interview method chosen is described in detail and its use in this study is justified. Next, the rationale for using narrative analysis is discussed in relation to other qualitative approaches to data analysis. Finally, various theoretical and philosophical ideologies that can inform theories about reality (ontology) and how this reality can be known (epistemology) are described, and the rationale is given for framing this research within a critical realist ontology and conducting it within an interpretivist and constructivist epistemology.

2.2 Background Context: Dream Diary Study (2021)

2.2.1 Participants

50 participants participated in the dream diary study; 25 diagnosed with DPDR and 25 matched controls. Controls had elevated anxiety and depression (to match as closely as possible with the DPDR group), but no cardinal DPDR symptoms. They were matched on age, sex and prescription medication for their mental health where possible. DPDR patients were recruited through existing research networks (e.g., Ciaunica & Charlton, 2018) and the charity *Unreal*, while controls were sought from University of Essex staff and student populations. All participants were aged 18 or over.

2.2.2 Procedure

Participants completed online daily dream diaries for 14 days, recording the presence and detailed contents of their dreams each morning, as soon as they woke up. Participants were asked for an explicit comparison of their dream selves with their waking selves in the context of their DPDR (see section 2.3.1 below). They rated their dream selves for cardinal DPDR symptoms (depersonalisation, derealisation, fragmentation) and provided a brief status report each evening, rating their waking selves for the same cardinal DPDR symptoms on the preceding day. They were also asked to what extent they felt "like in a dream" on the preceding day.

2.2.3 Materials

Copies of the questionnaires used in the dream diary study are at appendix A.

2.2.4 Ethics

The study received ethical approval from the University of Essex research committee (ETH2021-0794). All data was stored under pseudonymous and unique participation codes were used to identify and link data across days.

2.3 Current Study

2.3.1 Participants

This study followed up on the participants from the dream diary study who have a diagnosis of DPDR and who consented to being contacted for future research. Of 25 participants, one was excluded due to missing data. Four people did not consent to being contacted, therefore, 20 people were contacted to take part in the current study.

The purpose of this study is to explore how one's sense of self is experienced when awake and when dreaming. Therefore, of specific interest from the dream diary study was participants' answer to the questionnaire statements:

- In my dream(s) I felt more connected with my 'old', former self that I had before I developed DPDR
- In my dream(s) I experienced myself as disconnected in a similar way to my current waking DPDR self

Participants rated these statements in the morning following their dreams from 'strongly disagree' to 'strongly agree'.

Based on this, the 20 participants contacted were split into three groups:

- Those who answered 'strongly agree' to feeling connected to their former self in their dreams more than half the time (N=9)
- Those who answered 'strongly disagree' to feeling connected to their former self in their dreams more than half the time (N=8)
- Those who answered in roughly equal proportions (N=7)

2.3.2 Design

This study used a mixed-methods approach. Participants were interviewed to form the qualitative aspect, and secondary quantitative data from the dream diary study provides contextual information described below.

2.3.2.1 Quantitative Data

Secondary quantitative data from the dream diary study was included to provide an insight into the extent to which people with DPDR experienced their symptoms in dreams

compared to waking life and how this compared to controls. This was done by conducting three separate ANOVA tests and an independent samples t-test using SPSS, which compared waking and dreaming symptoms of depersonalisation, derealisation and fragmentation, as well as feeling "like in a dream" during the daytime, across both groups (all 50 participants).

2.3.2.2 Qualitative Data

There are various approaches to conducting qualitative research. It was decided a narrative approach was the most appropriate method of data collection and analysis. Interviews were guided by the Free Association Narrative Interview Method (FANIM; Hollway & Jefferson, 2000; 2013). A description of this approach and the rationale for its use are explained below.

The beginning of the twenty-first century saw a major growth in narrative and biographical methods for research, which sought to allow people to tell their own 'stories' or experiences directly, rather than having researchers write about them as an outsider (Ritchie et al., 2013). However, the precise definition of 'narrative' is contested (Reissman, 1993). Some researchers hold a broader view of 'narrative' serving as a metaphor for telling stories about one's life, including illness narratives in clinical literature, life stories, and narration about the past in psychotherapy. Others uphold a strict view of specific features a story must have to qualify as a narrative. For example, Labov (1972) suggested six elements of a 'fully formed narrative' including an abstract (summary of substance of narrative), orientation (time, place, situation, participants), complicating action (sequence of events), evaluation (significance and meaning of the action, attitude of narrator), resolution (what finally happened) and coda (returns the perspective to the present). Other researchers prioritise the importance of chronological sequencing and view narratives as being made up of a clear beginning, middle and end which can be detached and viewed as separate from the context in which they arise.

However, people's experiences are rarely so clearly bounded, leading some researchers to argue narratives should be tied together by themes rather than time (Michaels, 1982).

This research takes a psychoanalytic and culturally-oriented view of narrative. According to the psychoanalytic view of narrative, the psyche or one's thoughts are viewed as a form of language, and a narrative in itself. Narratives can signify unconscious emotions, as well as conscious thoughts and feelings (Squire et al., 2013). Using a culturally-oriented approach, this research considers narratives in context (Loots et al., 2013). It views identity as something which is actively constructed and performed in the moment between interviewee and interviewer. This includes considering the way one's story is organised, social-positioning, language used, how the interviewee positions the interviewer, and wider social and political discourses which influence the way one chooses to narrate their story, as well as how it is interpreted by the researcher (Loots et al., 2013).

2.3.2.3 Free Association Narrative Interview Method (FANIM)

One method of eliciting narratives is FANIM (Hollway & Jefferson, 2008). The authors summarise this approach in four principles, designed to facilitate the production of the interviewee's meaning frame, or gestalt:

1. Use open-ended not closed questions.

2. Elicit stories – turn questions into story-telling opportunities, for example "tell me about…". The story told, the manner and detail of its telling, points emphasised and morals drawn all represent choices made by the storyteller and contain significances beyond the teller's intentions.

3. Avoid 'why' questions

4. Follow up using respondents' ordering and phrasing - to respect and retain the interviewee's meaning frames.

Hollway and Jefferson (2008) explain FANIM is grounded in two principles: Gestalt Psychology, founded by Wertheimer (1938), and the Psychoanalytic method of free association. These concepts are explained below.

2.3.2.2 Gestalt

FANIM is partly based on the techniques used in The Biographical-Interpretative Method also called The Biographical Narrative Interview Method (BNIM). BNIM was founded by German sociologists, Schütze and Rosenthal (Schütze, 1976) and was originally created to interview holocaust survivors and former Nazi soldiers to produce uninterrupted accounts of their life story (Rosenthal, 1993; Schütze, 1992a; 1992b). It is based on the principles of Gestalt theory.

Gestalt is the German word for 'form'. The principle of Gestalt theory is that the whole is greater than the sum of parts (Hollway & Jefferson, 2001), thus applying this principle to qualitative research, Hollway and Jefferson (2001) explain that FANIM seeks to understand the 'whole' text of someone's narrative produced in an interview, as to understand meanings, we must place them in the context of the person as a whole (Bustamante, 2023). 'Whole' refers to all the information which could be gathered relating to a person taking part in research, for example from interview transcripts, but also from the researchers memories of the interview, field notes and things which may have been said about the interviewee by others (Hollway & Jefferson, 2008). To elicit 'whole' narratives using gestalt-informed methods, stories must be elicited 'intact', without affecting how it is constructed (Rosenthal, 1990).

2.3.2.3 Free Association

The first recorded psychological investigations into free association were conducted by Francis Galton (Galton, 1879a, 1879b), though it is now most commonly associated with Sigmund Freud, after free association became the fundamental rule of psychoanalysis. Analytical patients were encouraged to share their thoughts freely, regardless of how irrelevant or disagreeable their content may seem. It was thought the connections between a seemingly illogical sequence of ideas would reveal unconscious and underlying causes of the patient's problems.

According to psychoanalytic theory, distressing memories may be repressed to protect oneself from consciously acknowledging them and Freud believed that such thoughts or feelings could best be uncovered using free association (Jones, 2002). In the process of interviewing former soldiers, Schütze (1992a; 1992b) recognised a connection to Freud's idea of repression. He claimed soldiers were naturally defended about the subject, and thus a technique was required which could uncover "faded-out memories and delayed recollections of emotionally or morally disturbing war experiences" (p347). Initially, research methods based on free association entailed a single, open question "Please, tell me your life story" (Rosenthal, 1990), but has now evolved to include more questions. These methods assume participants may reveal unconscious thoughts or connections if they are free to structure their own narratives and make their own connections (Hollway & Jefferson, 2008).

These methods are favoured by those who believe structured interviews may suppress or influence participants' narratives, whereas participant-led methods are more unconsciously revealing than the meanings researchers might introduce (Hollway & Jefferson, 2008). In both free association and FANIM, interviewers withhold directly sharing interpretations to avoid influencing or directing interviewees (Jones, 2002). The reason is that the gestalt of the story; it's construction - the manner in which it is told and the aspects emphasised, all hold meanings

beyond the story-tellers conscious intentions (Aydin et al., 2012). Thus, narratives and associations made are guided by emotional motivations rather than rational logic or deliberate intentions (Hollway & Jefferson, 2008). To illustrate this, Hollway and Jefferson's (2008) study of people's experience of crime gave the example of asking "tell me about a time when you were fearful" rather than "what do you fear most?", with the latter likely eliciting a single-word answer rather than a story. This latter question also reveals the interests of the interviewer and may suppress or interfere with the meaning of fear to the interviewee.

This process of influence between two people was originally applied to patients and their analysts in psychoanalysis, and is termed 'transference' (feelings or ideas from the patient projected onto the analyst) and 'counter transference' (the reactions of the interviewers in response to this; Marks & Monnich-Marks, 2003). The idea of transference has since been applied to research contexts, for example, an interviewee may project certain feelings onto the interviewer (transference) who is subsequently forced to feel them and may react by being induced into a certain role, such as one of caring, annoyance or dismissal (Marks & Monnich-Marks, 2003). In the current study, such processes were recognised and reflected on in the researcher's journal, explained later.

2.3.2.4 Defended Subjects

The idea people repress certain thoughts and feelings from consciousness is a core tenet of FANIM. Hollway and Jefferson (2008) explain FANIM regards all interviewees as 'defended'. This is because of a fundamental belief of psychoanalytic theory that anxiety is inherent to all humans, especially those who experience threats to the self [i.e. DPDR] (Hollway & Jefferson, 2008). These defences are largely unconscious and intersubjective, meaning they are played out in relations with other people. They may impact how the meaning of something is conveyed, for example, events could be modified to be 'more acceptable'

(Hollway & Jefferson, 2008). Therefore, the authors criticise traditional semi-structured interviews which treat people as irrefutable experts of their own experiences, arguing this is not always the case, for example, if one represses certain experiences, knowingly or not, they may struggle to be transparent with the interviewer and also themselves (Hollway & Jefferson, 2008). The potential barrier this defensiveness could pose was recognised by the researcher, and its management is addressed later in this chapter.

2.3.2.5 Rationale for using FANIM

FANIM was considered the most appropriate interview method for this study for several reasons. As discussed in the introduction, the psychoanalytic perspective of DPDR emphasises that thoughts and feelings connected to one's self may be repressed or inaccessible to conscious thought. Similarly, this research deals with derivatives of conscious states and experiences within them, such as dissociated states, dream states and dissociation within dream states. The aforementioned research suggests accessing repressed or unconscious thoughts is best achieved by allowing participants to freely narrate their responses. While this study does not aim to uncover repressed memories, it seeks to provide a space for participants to explore aspects of themselves they may not be fully consciously aware of. Consequently, structured questions guided by conscious logic would be unsuitable if participants are not consciously aware of their thoughts. Additionally, many people with DPDR struggle with expressing themselves directly through language, therefore FANIM and its focus on transference and non-verbal communication may help with this. Given the focus on exploring unconscious phenomena and the dream life of these participants, an interview method that allows the unconscious to 'speak' through free association is epistemologically appropriate. Finally, narrative approaches recognise distinct cultural or contextual factors that influence experiences, and which are common in under-researched populations.

2.4 Materials

Interviews primarily sought to explore how identity is experienced and made sense of by people with DPDR in their dreams and in waking life. The questions used were open-ended, to create a participant-led process (see appendix B for interview schedule).

2.5 Procedure

2.5.1 Recruitment

Participants' email addresses were obtained from the dream diary study database and recruitment emails were sent by the principal researcher of that study (also the primary supervisor of the current study). The email (appendix C) invited participants to take part in the current research and contained an information sheet (appendix D), providing further descriptions about the aims and interview process. A consent form (appendix E) was also attached. Participants were asked to sign and return the consent form by email to the researcher, should they wish to take part. Once received, the researcher remained in contact with participants to arrange a suitable time and date for the interview to take place on Microsoft Teams.

2.5.2 Interview Procedure

Each participant was interviewed once. At the start of each interview, informed consent procedures were reiterated and participants were asked to confirm they were comfortable with interviews being video recorded for transcribing purposes. The length of interviews was unconstrained and depended on how much participants expanded on their experiences. This allowed participants to more fully immerse themselves in the concept of free association. The resulting video files were stored on an encrypted hard drive along with the automatic, anonymised transcriptions produced by Teams.

Before the interview commenced, participants were reminded about their participation in the dream diary study. The researcher explained whether the data from this study revealed that at the time they could retrieve an 'authentic' sense of self in their dreams or not. It was then explained that the current interview aimed to understand more about what this meant to them and to expand on their experiences of retrieving an authentic sense of self.

While qualitative methodologies are historically recommended to take place face-to-face (Keen et al., 2022), online interviews were chosen for two main reasons: first, to manage researcher time and availability. Second, participants were based internationally. Therefore, even if some could be reached in person, holding some interviews in person but others online may impact the researcher-participant relationship and lead to differing environments which may reflect in the type and amount of information shared.

Some researchers caution that interviewing people remotely could impede on the ability to build rapport; restricting the depth of interactions (Irvine et al., 2013), or impeding the reading of non-verbal cues which some argue could damage participant trust and engagement (Chen & Neo, 2019). However, following COVID-19, a global uptake in remote data-collection was prompted. The recording and transcribing abilities of video-calls are not only practically useful regarding time, travel and cost, but may support greater ecological validity, due to the absence of intrusive, visible recording devices (Keen et al., 2022). Researchers can reach a global sample and participants can choose a safe, comfortable environment from which to conduct the interview (Keen et al., 2022), which is particularly relevant for the current study. Furthermore, it is recognised that virtual interview interactions can emulate natural conversation (Roberts et al., 2021), particularly through techniques such as: researchers having warm, open on-camera body language, thanking participants for their time, checking for technical problems and reminding participants of their rights to pause or end the interview at any time – including pausing recordings (Keen et al., 2022; Shankley et al., 2023). In light of

the discussion around 'defended subjects', these steps were recognised as particularly important ways of minimising the barriers to engaging in open and meaningful conversations.

Notably, the researcher has extensive experience of conducting online therapy for PTSD. These experiences were useful to draw upon when building rapport with the current participants. For example, it contributed to the awareness of coming across as non-judgemental, the impact of tone, language, and non-verbal communication on participants' ability to talk about difficult or traumatic experiences. As interviews were one-off, and because the style of interview required participants to speak openly with minimal input, it was anticipated that it may take longer for participants to feel comfortable to speak as openly as was hoped. Therefore, active listening techniques and emotional validation were of importance to the researchers approach.

2.6 Analysis

Some qualitative analysis methods are criticised for fragmenting and de-contextualising experiences (McAllum et al., 2019), as to see patterns across the data, segments of data are clustered, removing statements from their original context, such as in thematic analysis. Codes are de-contextualised further by fitting them into broader, more abstract and conceptual themes. Charmaz (2003, p269) explained that this process of "cleaning up subjects' statements" can lead to researchers only selecting data which fits their emerging framework, sometimes privileging one participant's perspective over others.

However, narrative approaches are thought to allow for chaotic experiences to be re-framed in a predictable order or to highlight tensions (Wong & Breheny, 2018), a feature which would be highly appropriate for DPDR which is itself experienced as fragmented and disjointed. Narrative analysis signifies a departure from experience-centred models into

context-rich frameworks, paying attention to social discourses and factors which influence narratives outside of the experience itself (Squire et al., 2013).

Although they do not specify a technique for analysing FANIM interviews, Hollway and Jefferson (2001) support the idea that fragmentation of traditional coding methods goes against the principle of Gestalt. They used a case study to illustrate the use of a narrative approach to analyse a FANIM interview. Their technique combined the use of subjective interpretations and psychological and social theory to draw reasonable inferences about interviewees' narratives and drew attention to contradictions which could signify (un)conscious mental conflict.

As described, the definition of narrative methods is contested, and depending on one's definition, the approach to analysis will also differ. There is no systematic way to perform narrative analysis, with researchers organising narratives around time or theme – discussed earlier – or the oral properties of the story such as pitch, pauses and poetic stanzas (Gee, 1986). However, it has been contested that these methods disregard the interaction and relationship between the storyteller and the researcher (Riessman, 1993). Therefore, this research followed the seven stages of analysis outlined by Fraser (2004), described below. This method was thought to be in-keeping with the style of narrative analysis used by Hollway and Jefferson (2001) and was considered to holistically unify various narrative approaches by considering not just what is said or how, but also why, and the feeling or experience behind it (Gubrium & Holstein, 1998). The issue of de-contextualisation is addressed in multiple phases of analysis, by considering the researcher's influence and wider systemic factors.

Phase One: Hearing The Stories, Experiencing Each Other's Emotions

Phase one began during data collection. Throughout this stage, the researcher maintained a detailed diary documenting observations, reflections and emerging thoughts

immediately after each interview to ensure reflections were accurate and true to the time of interview. The diary was guided by prompts suggested by Fraser (2004; appendix F) and advice from Giovanna et al. (2019) who stipulate the importance of noting paraverbal information (modification of tone, pitch, pacing, silences, long pauses) and non-verbal cues (posture and movements, eyes movements, facial expressions). Such details are important to capture as they may influence subsequent interpretation of the narratives (Fraser, 2004).

Phase Two: Transcribing the Material

Having a video recording of interviews as opposed to audio allowed for nuanced analysis of verbal and non-verbal cues. After each interview, recordings were reviewed and numerous corrections were made due to inaccuracies in automated transcriptions. Reflections from phase one were incorporated, for example, annotating instances where closed questions were asked and reflecting on how these could be rephrased to elicit more detailed responses, thus showing how meaning was interactionally accomplished (Paget, 1983). Contextual information including technological issues were also noted. This reflective process enabled the researcher to critically consider their role in the research and make adjustments to improve the quality of data collection in future interviews.

Phase Three: Interpreting Individual Transcripts

Use of an existing framework in analysis can form part of the process of engaging in a discourse with the scientific community (Andersen & Kragh, 2010), thus, theory was brought in during this phase. In his work exploring how illness is experienced and expressed in people's narratives, Frank (1995) identified three types of narrative were often told: stories of chaos, restitution or quest. He explained: "a narrative type is the most general storyline that can be recognised underlying the plot and tensions of particular stories" (p75) and that narrative types

can be used as 'listening devices' or ideas which can guide the listener in understanding the different focus that narratives can have. Frank (1995) suggests that because stories of illness can be complex, listening devices help people pay closer attention to what is being said and 'sort out' the threads of stories which 'mix and weave to form a complex picture' (p76). This was considered a useful and relevant methodology to follow in the context of identity, a concept which the preceding literature has shown is extremely subjective and difficult to define.

One framework which conceptualises identity seemed to encapsulate the markers of DPDR described in the systematic literature review. This theoretical framework was proposed by Bamberg (2012) to describe the *function* of narratives in actively forming and navigating identity, rather than identity being something we simply have or are (Bamberg, 2011). Bamberg identified three dimensions along which identity is navigated: 1. Constancy and change across time, 2. Sameness vs difference and 3. Agency.

The first dimension is constancy and change across time. This means speakers position "who they are in terms of some form of continuity", and construct their identity in terms of "some change against the background of some constancy (and vice versa)" (p6). For example, attempts to integrate past and present into a coherent whole. Bamberg (2012) suggests these narratives focus less on how or whether someone has changed and more on how this dilemma is constructively navigated. The second dimension is sameness vs difference which Bamberg (2012) proposes is the way speakers position themselves in relation to others. They do this by aligning with or positioning themselves in contrast to others, so that individual and group identities become visible. Bamberg (2011) explains integration and self-differentiation from groups may be negotiated unconsciously, and he draws on Hollway and Jefferson's (2000) concept of unconscious defences to explain this. Finally, agency refers to the way people view themselves as a bodily agent, as "bodily present" and "interactively involved" (p8). People mark themselves as either high agency (self as strong, in control and self-determined) or low

agency (self as encompassing a "victim role" of being less influential, powerful or responsible) (p8). Bamberg's identity theory has been applied across various fields, including narrative psychology, sociolinguistics, youth and adolescent development, and cross-cultural psychology to explore how individuals construct and negotiate identity through language and social interaction.

Frank (1995) cautions against trying to make a narrative "fit" into a certain structure and encourages listeners to propose new narrative types where necessary (p76). Therefore, the researcher held in mind the three listening devices proposed by Bamberg (2012) when analysing participant interviews to guide understanding of how identity is constructed. However, it was noted when narratives did not fit Bamberg's description and thus was not blinded by pre-existing narrative types. This approach aligns with the 'in vivo approach' to using theory in qualitative research proposed by Andersen and Kragh (2010) who emphasise that no researcher is free of pre-conceptions about a topic, and that use of theoretical predispositions should be embraced and reflected upon rather than avoided. They too explain that theories can guide ones interpretation and be updated or changed if it does not fit.

Transcripts were colour coded to denote which narrative type they fit into. They were coded by line to describe the experiences within each narrative type (example at appendix G). Furthermore, prompts listed by Fraser (2004, p190) were used to note how narratives were told. Close attention was paid to vocal inflections, considering what they might signify (such as emphasising a point) or the underlying emotions. The choice of words and their emphasis provided insights into the meanings participants assigned to their experiences. Other vocalisations and non-verbal gestures were highlighted and annotated. This helped to identify contradictions, notable silences or pauses which could suggest disagreement, boredom or distress.

Phase Four: Scanning Across Different Domains of Experience

Fraser (2004) explains data should be examined through four critical lenses: structural, cultural, interpersonal and intrapersonal. Using these lenses acknowledges various factors which influence people's experiences and the way they are told.

From a structural perspective, the researcher considered how broader social and systemic factors such as healthcare systems influenced participants' experiences and narratives. Culturally, the researcher examined how beliefs and values regarding mental health, selfhood and dreams affected participants' interpretations and meanings ascribed to their experiences. The interpersonal aspect involved considering the influence of interactions with family, friends and healthcare professionals on identity. Finally, intrapersonal analysis focused on participants' internal psychological processes and reflections and how this influenced the way they processed their dream experiences, emotions, and the impact on their self-concept and identity. As in the next phase, these lenses were held in mind when applying codes, and reflections were noted to inform interpretations made in the final write up.

Phase Five: Linking 'the Personal with the Political'

Phase five involved linking personal narratives to broader societal and political discourses and critically examining how dominant discourses and social conventions shaped participants' stories about their experiences of DPDR and identity. An example of this can be seen in the narrative analysis by Phoenix (2013), who discussed how cultural understandings of racism influenced how participants constructed their identity by explaining certain moralistic views or experiences. The choice to explain these particular aspects of their identity were influenced by the race and assumed knowledge of the researcher by the interviewee.

In the current study, examples included considering the role of societal stigmatisation of having mental health difficulties or receiving a diagnosis, and demographic factors including

class, gender, race, sexual orientation, age, disability, religion and geographical location. The researcher discussed the influences of race and culture on how participants' families understood their experience of DPDR. Furthermore, they reflected on how the decade in which people in this study were diagnosed with DPDR varied, bringing with it a diverse range of experiences and societal norms which governed them at the time. Throughout this process, the researcher ensured to distinguish clearly between the participants' accounts and their own analysis, ensuring participants' voices were not overshadowed by their own interpretations.

Phase Six: Looking for Commonalities and Differences Among Participants

Invariably, phase six took place throughout phases three to five, and involved looking for commonalities and differences between narratives on various aspects such as the content, style and tone. The codes created in phase three were tabulated and grouped by narrative type. From this, similar codes were grouped together and several subthemes emerged. A process of iterative comparison and refinement ensured the breadth of experiences was encapsulated under each subtheme and narrative type.

Phase Seven: Writing Academic Narratives About Personal Stories

The final phase involved selecting narratives which accurately represented the subtheme and narrative type it came under. Alongside the core narratives which represent a subtheme, the researcher selected stories which were contradictory, interesting or surprising to cover the breadth of experiences. It is recognised that the stories selected and presented in the results do not claim to present 'the truth' or 'right' knowledge (Fraser, 2004), but is one of many ways of representing the stories available.

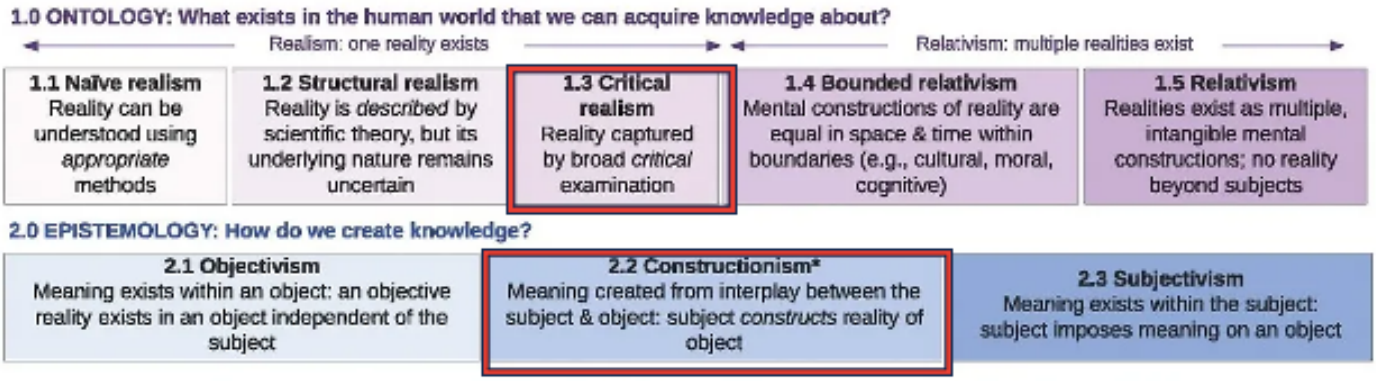
2.7 Ontological and Epistemological Positioning

2.7.1 Ontology

Ontology plays a fundamental role in shaping research design, by influencing the research questions, paradigm, methodology, data collection, analysis, validity, reliability, and ethical considerations of a study. Understanding and explicitly stating one's ontological stance is essential for ensuring coherence and rigor in research (Richtie et al., 2013). Ontology refers to the extent to which research can represent reality and is concerned with whether there is a shared social reality or only multiple, context-specific ones (Ritchie et al., 2013). This study takes a critical realist ontological position. As shown in figure 5, this stance sits between realism and relativism. Within these broad positions exists a number of more nuanced perspectives.

Figure 5

Map of Ontological Positions (Moon & Blackman, 2014)



2.7.1.1 Realism

Researchers working within the realist paradigm believe that there is an external reality which exists independently of people's beliefs or understanding of it. They believe the world is rule-bound, and that the truth can be discovered using appropriate methods. Most quantitative research assumes this stance (Richtie et al., 2013).

2.7.1.2 Relativism

In stark contrast, relativism rejects the idea of a single truth. Relativists argue there are many versions of reality, only knowable through the human mind and socially constructed meanings, and that no reality exists independently of these (Ritchie et al., 2013). Any data collected only represents one version of reality.

2.7.1.3 Critical Realism

Situated between these two contrasting ontological positions is critical realism. Similar to realists, critical realists hold that there is a reality out there (rather than multiple realities), but emphasise the range of factors which influence the way this reality is interpreted. They believe data can inform us about reality but do not view this as a direct mirroring (Harper, 2011). Research under this paradigm aims to capture reality in all its complexity and depth and accept a range of interpretations about that experience can be made (Ritchie et al., 2013). This is therefore the most appropriate approach for the current study as it allows for an exploration of how individuals make sense of DPDR while recognising the influence of wider discourses and interpersonal dynamics, which a purely realist or relativist position may overlook.

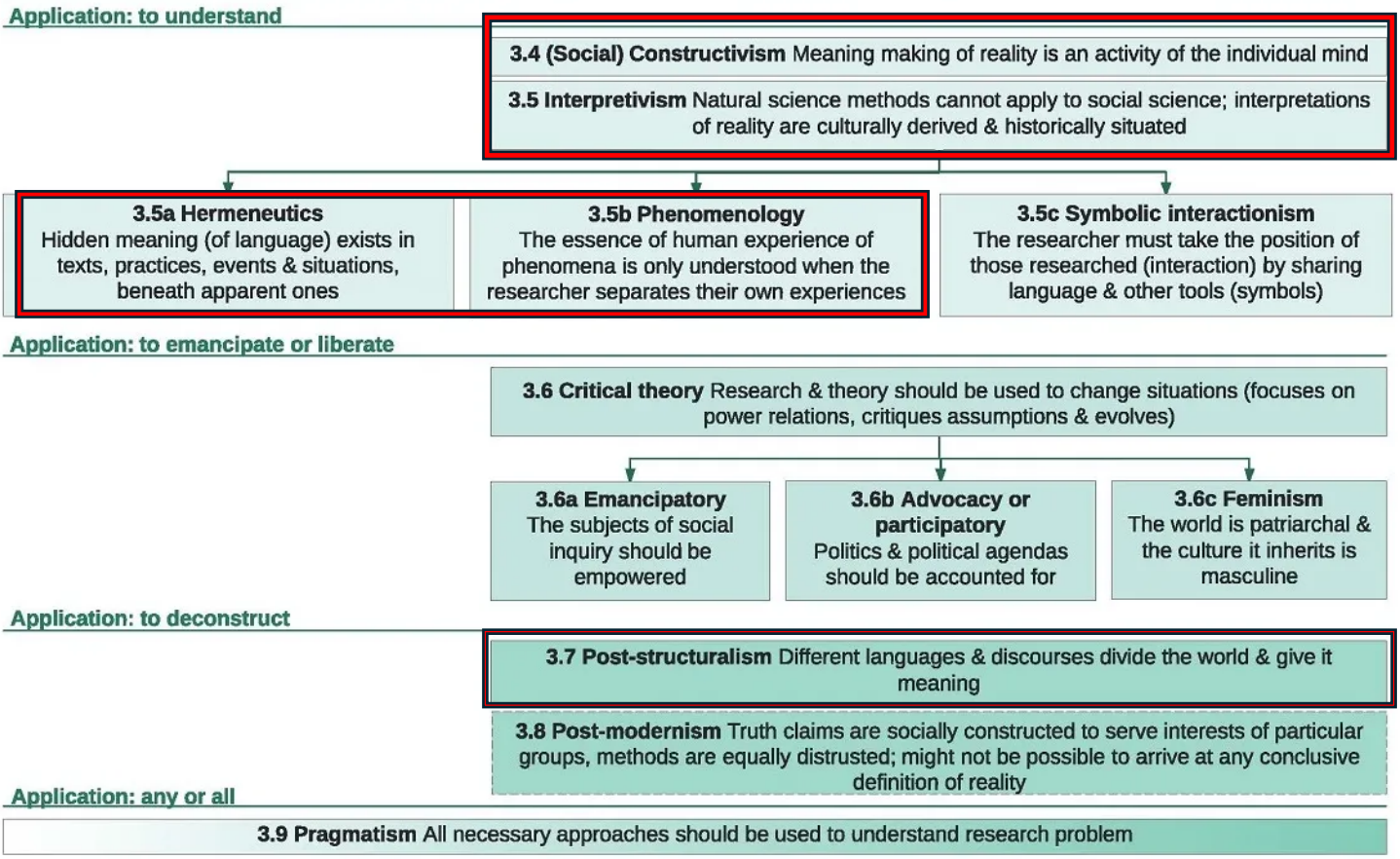
2.7.2 Epistemology

Epistemologies are the philosophies which discern the best way to collect data and the validity and usefulness of knowledge acquired, for example its transferability to other people or situations (Moon & Blackman, 2014). The four epistemologies most commonly used in qualitative research are positivism, post-positivism, social constructivism and interpretivism (Ritchie et al., 2013).

FANIM draws on the paradigms of constructivism and interpretivism. It is also rooted in a post-structuralist paradigm (Scheffelaar et al., 2021). These epistemologies are represented in relation to one another in figure 6, and are explained within the context of FANIM.

Figure 6

Map of Epistemological Positions (Moon & Blackman, 2014)



2.7.2.1 Interpretivism and Constructivism

Interpretivism emphasises that individuals craft and shape meanings as they recount stories, sometimes unintentionally or without conscious knowing (Corbally & O'Neill, 2014). It seeks to understand how individuals attribute meaning to their subjective experiences and believes the truth of these experiences depends on how they are interpreted by others (Corbally & O'Neill, 2014). In accordance, FANIM allows participants to freely express narratives,

providing people the opportunity to convey their unique interpretations and understandings of their experiences; applying the clinical principles of psychoanalytic free association to a research context.

The additional focus in FANIM on the researcher-participant relationship also aligns this approach with constructivism. Constructivism emphasises that meaning is created within a specific context; a researcher-participant dynamic, and encourages researchers to consider the broader context in which narratives are situated (Ide & Beddoe, 2023). Like FANIM, constructivists recognise stories told during interviews may not be a neutral account of pre-existing reality. Instead, narratives are shaped by participants' interpretation and the interview process itself, such as how questions are structured and the amount or type of feedback given by the researcher as part of the interview dialogue.

2.7.2.2 Post-Structuralism

These approaches, including psychoanalysis, sit within a post-structuralist paradigm (Squire et al., 2013). According to post-structuralism, the idea of a fixed truth or objective reality is challenged. Social reality and meanings are constructed differently by individuals, based on contextual factors such as culture or personal history. Furthermore, language is not perceived as value-neutral (Scheffelaar et al., 2021), rather, it recognises that a speakers words may not be interpreted or understood in the same way by the person receiving those words (Hollway & Jefferson, 2008; Spector-Mersel, 2010). Thus, a critique of traditional semi-structured interviews is that by constructing certain questions which one wishes to explore, the interviewer inherently assumes there is shared meaning between participants and researchers, attached to the words or phrasing which they use to structure their interview questions (Hollway & Jefferson, 2008). Furthermore, narratives are reconstructed and reinterpreted by the interviewer through their own knowledge framework, values, beliefs and emotions

(Scheffelaar et al., 2021). For this reason, it is important to place the research content, the researcher, and analysis process within the social and cultural context (Elliott et al., 2005). Thus, the process of self-scrutiny and reflexivity is central to Hollway and Jefferson's (2008) definition of social research and narrative analysis methodology.

2.8 Researcher Position Statement

Before the doctorate, I worked as an Assistant Psychologist in a forensic service for women serving community orders. Here, the vast majority of women I delivered therapy to had C-PTSD and many experienced dissociation, though looking back, I did not recognise this at the time. Initially, I lacked a deep understanding of dissociation and its profound impact on therapy, memory, and self-perception.

During my first year of the clinical doctorate, I worked in a service specialising in delivering therapy for PTSD and I received extensive training on managing dissociation and adapting therapeutic sessions accordingly. Despite this training, I had never come across the term DPDR, only more broadly 'dissociation'. Looking back with my current knowledge, I can identify distinct features of both DP and DR in the clients I saw, and I reflect now on the role I played as a clinician bearing a lack of knowledge in treating people with this disorder. I hope this research will aid a deeper exploration into this type of dissociation, enriching my own and other clinicians' understanding and approach to therapy and trauma.

Through clinical training, I am still learning about where my specialist interests lie, and I believe trauma to be one of them. Furthermore, my interest in the Power Threat Meaning (PTM) framework to formulation has been pivotal in shaping my approach to trauma and dissociation. This framework, developed as an alternative to traditional diagnostic models and emphasises the importance of understanding the meanings individuals ascribe to their experiences and ways of coping. It highlights the role of power dynamics and social context in

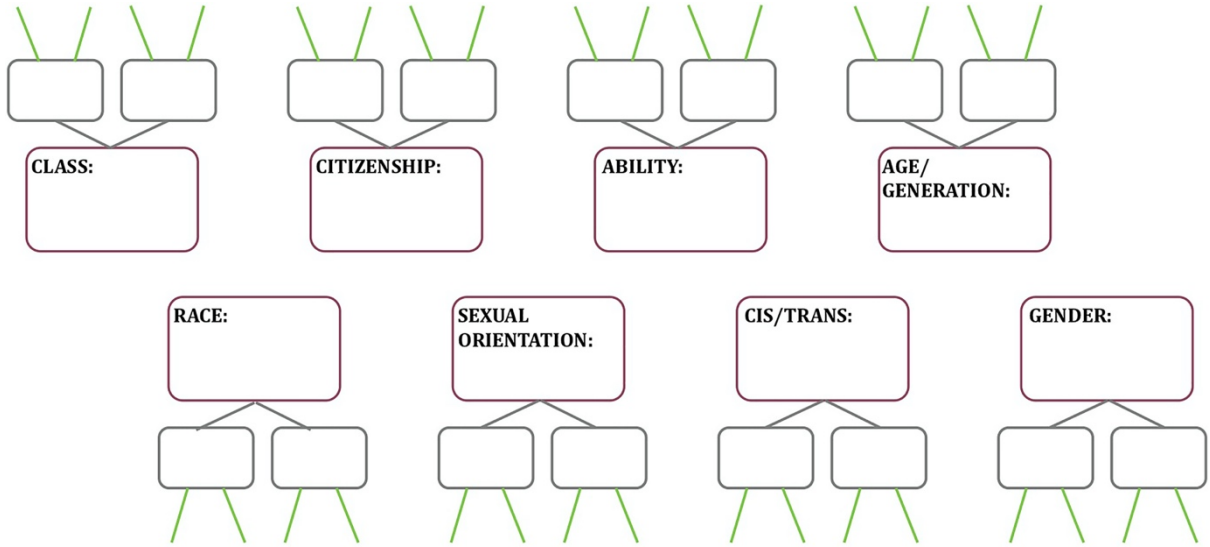
the development and manifestation of psychological distress. By focusing on the narratives and personal meanings that individuals attach to their experiences, the PTM framework aligns with my aim to delve deeper into how people with DPDR make sense of their condition and how it shapes their sense of self. Ultimately, this is what led me to adopt a qualitative methodology for my research, informed by psychoanalytic principles, valuing the open-ended style that allows for a deep, nuanced understanding of participants' experiences.

As someone who has personally grappled with questions of identity and self-concept, particularly in the context of recovering from mental health difficulties, I bring a reflective and empathetic lens to my research. My clinical practice has equipped me with the skills necessary to engage meaningfully with individuals experiencing DPDR.

Utilising the social identity map in figure 7, I spent time reflecting on how my personal characteristics may shape the researcher-participant dynamic as well as my interpretation of the data. For example, ensuring cultural competence and sensitivity in my research is essential, and I recognise that the subjects of mental health, trauma and identity are largely impacted by ones cultural attitudes and beliefs. I thought about my position as a white female from a middle-class background and I held in mind to consciously reflect on any unconscious biases I may have through the reflective journalling process and through the ideas of counter-transference, as these could impact my interpretation of the data.

Figure 7

Social Identity Map (Jacobson & Mustafa, 2019)



2.9 Ethical Considerations

This study received ethical approval from the University of Essex research committee (ETH2324-0066) (appendix H). It was made clear to participants on the information and consent forms that they are free to withdraw at any time. All identifiable information was only made available to the research team and was kept confidential. Data was stored in a secure and encrypted online database (University of Essex Box Drive). No known risks were identified to taking part, however, interviews involved participants talking about sensitive topics such as their own emotional state and mental health diagnosis, which some may find upsetting. Due to the nature of free association, it was anticipated participants may also find that their narratives led them to talk about surprising or unexpected emotional territory. It was considered that should participants find the conversation upsetting, they would be free to take a break or withdraw from the study at any time and this was made clear before interviews began. Additionally, the information sheet provided details of charities and support services they can turn to (Samaritans, Mind, Unreal) and recommended they speak to their GP if they felt affected as a result of talking about their DPDR experiences.

2.10 Dissemination

The findings of this study may be relevant to several journals which publish research on phenomenology, consciousness, dreaming and cognition. It is also intended to separately publish the systematic literature review from this thesis. Suitable journals identified include *Phenomenology and the Cognitive Sciences*; *Dreaming*; or *Consciousness and Cognition*.

The findings of this research were presented as a poster at *The International Society for the Study of Trauma and Dissociation (ISSTD)* in March 2025. This annual international conference promotes clinically-effective and empirically-based and theoretically-informed information about trauma and dissociation. Another relevant conference to consider is *The European Society for Trauma and Dissociation (ESTD)*, or conferences focussing on consciousness and dreaming, including *The Association for the Scientific Study of Consciousness* and *Toward a Science of Consciousness (TSC)* or *The International Association for the Study of Dreams (IASD)*.

The results of this study may be relevant to multiple audiences including the participants, DPDR charities, policy makers and service providers involved in DPDR diagnosis and treatment, academics and the public. Disseminating these findings with charities would be beneficial as their reach may help spread awareness among a wider population including people with lived experience of DPDR, their carers and families. Relevant charities may have a specific focus on DPDR or DPDR may inform part of the overall work they do. For example, *Unreal, Young Minds* and *Anxiety UK,* who could be contacted by email.

To share the findings with people inside and outside of academia, the results could be published and made accessible via open access or Google Scholar. Kudos (https://www.growkudos.com/) and ImpactStory (https://impactstory.org/) are websites through which researchers can spread awareness of their publications to people with and

without an academic background. The websites can aid dissemination by sharing links to the full publication, providing a lay language explanation, impact statements and links to additional related content. There is also a process to share this information on social media and monitor the interaction with posts, for example, tweets, visits, downloads and views.

Findings could be disseminated to healthcare providers involved in the diagnosis and treatment of DPDR, including psychologists, GPs and services treating people with PTSD. They could be contacted through social media (Facebook, Twitter, LinkedIn) to share posters or lay language briefs of key findings and recommendations. Specific groups could be reached using hashtags. Finally, all participants asked to be contacted regarding the results of this study and will be contacted by email.

Results

3.1 Chapter Overview

This chapter presents the research findings, starting with an overview of the sample and demographic characteristics. Next, statistical analysis comparing the DPDR and control group waking and dreaming symptomology are presented as collected in the dream diary study. Finally, the results of the narrative analysis are presented.

3.2 Sample

Twelve people participated in the research. One further participant expressed interest in taking part but did not respond to contact to arrange an interview.

In the interview, participants reported a subjective account as to whether their DPDR symptoms had changed since the dream diary study, such as in frequency or intensity, and responses are recorded in table 4 along with other demographic information. None considered themselves fully recovered, although two participants reported significant improvements in symptoms. CDS scores, medication and comorbidities were reported from the dream diary study.

Table 4

Participant Demographics

Pseudonym	Sex	Age	Ethnicity	Self-reported age of DPDR onset	Year of formal DPDR diagnosis	Symptom frequency	Comorbidities	Medication/ treatment	Cambridge Depersonalisation Scale Score (Range 0-290)	Symptom change since 2021
Serena	Female	37	British	Age 3	2018	Chronic	Eating disorder not specified, anxiety, depression	Medications for mood not specified. 'therapy'	188	No but more aware of symptoms and their impact
Elena	Female	55	Spanish	Unsure	1998	'Not often'	Personality disorder	sertraline, amisulpride,	213	Unsure
Dominic	Male	37	Nigerian	Age 11	2017	Chronic	No	No	254	No
Wilana	Female	44	Nigerian	Age 13	2020	Chronic	No	Talk Therapy, CBT, Sertraline	149	Slightly less 'random thoughts' about existence
Elliot	Male	59	British	Age 10	1995	Chronic	Anxiety, depression, Eating disorder not specified	Lorazepam, Zopiclone, private counselling	225	No 'remains constant and severe'
Lucas	Male	34	Peruvian	Age 15	2020	'every now and then'	No	No	114	Feels mostly recovered. Participant described feeling a subjective rating of 3-4 out of 10
Nathan	Male	34	British	Age 18	2018	Chronic	No	Venlafaxine	248	No

River	Non-binary	23	German	Age 10	2018	Chronic	Generalised and social anxiety	Behaviour Therapy	186	No but feels more 'at peace'
Daniel	Male	53	British	Age 15	1999	Chronic	No	Sertraline	211	No but feels better able to cope
Nina	Female	52	Chilean, American	Age 30	2012	Chronic	No	SSRIs, lamotrigine, 'therapy'	154	No
Leo	Male	34	British	Unsure	2015	Chronic	No	No	109	DP remains unchanged but DR has improved: feels more connected to body and 'things look more familiar and real'.
Kai	Male	40	Moroccan/ English	Age 14-15	2014	Chronic	No	Isocarboxazid, Quetiapine	93	No

3.3 Dream Diary Study: Quantitative Results

As described in the methods, participants were grouped as to how connected to their 'former' sense of self they felt in their dreams (as rated in the dream diary study). Table 5 shows a comparison of this original grouping against the current study. Changes were discerned by the researcher based on conversations from the current interviews. Most people stayed the same, while those who experienced a change tended to feel more disconnected from their former self compared to the time of the dream diary study.

Table 5

Changes in Perceived Connection to Former Self in Dreams Over Time

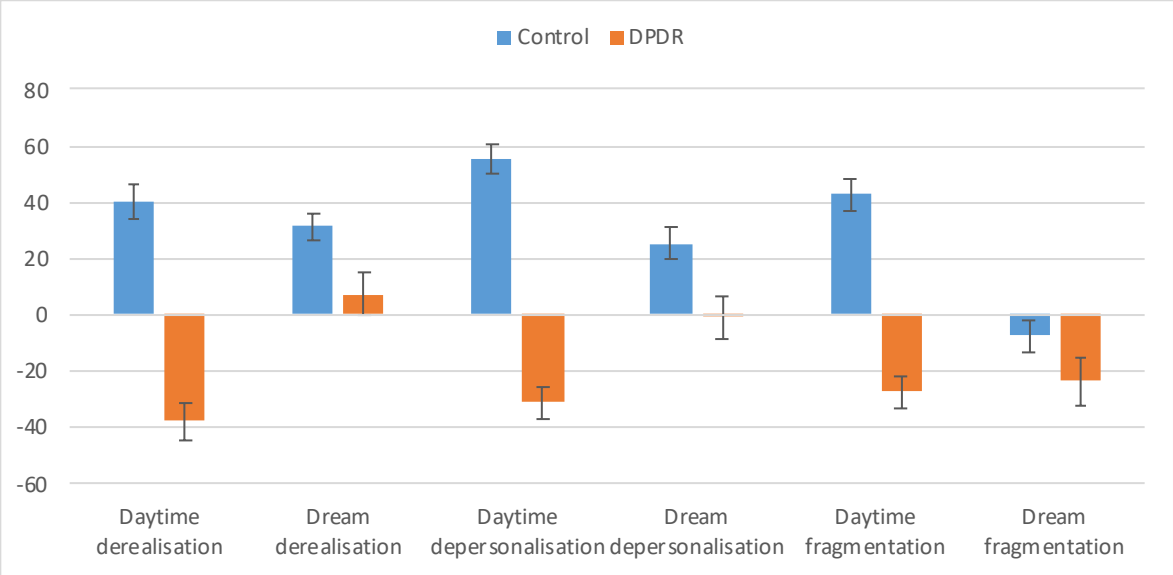
Participant	Original grouping	Stayed the same	Became more connected	Became more disconnected	Other change
River	Mostly Disconnected	X			
Elliot	Mostly Disconnected	X			
Wilana	Mostly Disconnected		X		
Kai	Mostly Disconnected	X			
Dominic	Mixed	X			
Daniel	Mixed				Rarely dreams due to medication
Serena	Mixed			X	
Nina	Mostly Connected			X	
Leo	Mostly Connected	X			
Nathan	Mostly Connected			X	
Elena	Mostly Connected			X	
Lucas	Mostly Connected	X			

Note: mostly connected/disconnected = participants felt connected or disconnected to the sense of self they had before the onset of DPDR in their dreams most of the time. Groupings were calculated by the researcher, where 'most of the time' indicates that more than half of their dreams were connected/disconnected to their former sense of self. 'Mixed' grouping indicate an equal split.

Quantitative data from the dream diary study was analysed to provide an insight into DPDR symptoms in people with DPDR (N=25) compared to matched controls (N=25) in waking and dreaming states. The results of the ANOVA tests comparing self-rated experiences of depersonalisation, derealisation and fragmentation symptoms across day and night are described below and represented visually in figure 8.

Figure 8

Mean ratings of depersonalisation, derealisation and fragmentation symptoms for DPDR and control groups during dream diary study



Note: 0=neutral, negative values indicate more DPDR-like symptoms, positive values less DPDR-like symptoms

Derealisation

To measure waking and dreaming experiences of derealisation, each morning and night, participants indicated where they fell on a sliding scale in response to the statement: "Today I felt/In my dream(s) I felt: very disconnected from the world vs. very immersed in the world". A mixed ANOVA examined derealisation across day and night. There was a significant main effect of group, with the DPDR group (M = -15.34, SE = 4.86) experiencing more derealisation than controls (M = 35.67, SE = 4.86), $F(1,48) = 55.06$, $p < .001$, $\eta p^2 = .53$.

There was also a significant main effect of time, $F(1,48) = 10.31$, $p = .002$, $\eta p^2 = .18$, with higher derealisation at night during dreams for both groups.

A significant group x time interaction, $F(1,48) = 23.14$, $p < .001$, $\eta p^2 = .33$, showed the DPDR group exhibited a larger difference in derealisation between day- and nighttime than controls. Specifically, the DPDR group had high daytime derealisation (M = -37.80) but showed partial relief in dreams (M = 7.12). In other words, DPDR participants felt slightly more "real" in their dreams compared to waking life, suggesting sleep may provide temporary relief from derealisation symptoms.

Depersonalisation

To measure waking and dreaming experiences of depersonalisation, each morning and night, participants indicated where they fell on a sliding scale in response to the statement: “Today I felt / In my dream(s) I felt: very disconnected from my bodily sensations and emotions vs. very connected with them”. A mixed ANOVA examined depersonalisation across day and night. There was a significant main effect of group, $F(1,48) = 69.59$, $p < .001$, $\eta p^2 = .59$, with the DPDR group (M = -16.03) experiencing significantly more depersonalisation than controls (M = 40.44).

There was no significant main effect of time, $F(1,48) = <.001$, $p = .988$, $\eta p^2 = <.001$, suggesting no significant day to night differences overall.

A significant group x time interaction, $F(1,48) = 29.50$, $p < .001$, $\eta p^2 = .38$ suggests the way depersonalisation changes from daytime to nighttime differs between groups. Controls indicated they felt ‘very connected with bodily sensations and emotions’ during the day (M = 55.56) and in their dreams (M = 25.32), while people with DPDR felt very disconnected during the day (M = -31.23) and neutral in their dreams (M = 0.82), again suggesting a partial relief from their depersonalisation symptoms during sleep.

Fragmentation

To measure waking and dreaming experiences of fragmentation, each morning and night, participants indicated where they fell on a sliding scale in response to the statement: “Today my reality felt/In my dream(s) I felt: very incoherent/fragmented vs. very coherent”. A mixed ANOVA showed a significant main effect of group, $F(1,48) = 36.69$, $p < .001$, $\eta p^2 = .43$, with the DPDR group ($M = -25.45$) experiencing more fragmentation than controls ($M = 17.66$).

A significant main effect of time, $F(1,48) = 15.57$, $p < .001$, $\eta p^2 = .25$, indicated higher fragmentation at night for both groups. A significant interaction between group and time, $F(1,48) = 20.79$, $p < .001$, $\eta p^2 = .30$, indicated that changes in fragmentation from day to night differed between groups. The DPDR group experienced a more pronounced change in fragmentation from day- to nighttime compared to controls. The control group felt very coherent during the day ($M = 42.86$) but more incoherent in their dreams ($M = -7.54$), while the DPDR group felt incoherent in the day ($M = -27.27$) as well as in their dreams ($M = -23.64$).

Subjective Daytime Experience of "Feeling like in a Dream"

Finally, an independent t-test compared the subjective experience of feeling "like in a dream" between the DPDR and control groups. Each evening, indicated where they fell on a sliding scale stating: “Today I felt very much like “in a dream” vs. “today I felt very much “fully present” and “real”.

A significant group difference was found $t(48) = 9.65$, $p < .001$, Cohen’s $d = 2.73$, with the DPDR group reporting significantly stronger dreamlike feelings ($M = -33.00$, $SD = 32.41$) than controls who felt more “fully present” and “real” ($M = 49.90$, $SD = 28.18$) during the daytime.

Across all measures, individuals with DPDR experienced significantly higher symptoms of derealisation, depersonalisation and fragmentation compared to controls. The results also suggest that for people with DPDR, dream experiences may provide some relief from symptoms of depersonalisation and derealisation. However, fragmentation showed continuity from day- to nighttime measures, suggesting that people with DPDR experience their reality as incoherently as their dreams. This conclusion is further supported by the heightened daytime experiences of feeling "like in a dream" reported in this group compared with controls.

3.4 Narrative Analysis Results

3.4.1 Narrative Structure

Interviews lasted between 1:22:57 and 2:04:54 (average length 1:40:33). There were temporal differences in the way narratives were structured, with some people focussing more on present experiences and others more on past.

These differences were most notable in response to two interview questions which referenced time: "Can you describe the differences between your sense of self before experiencing DPDR and the one you currently experience?" and "Can you tell me what your dream life is currently like?". In response to the first question, the amount participants described their past or current self varied greatly depending on factors including age of DPDR onset, how strong their sense of self felt before DPDR, how strong their memories of the past were, or how difficult the past was to talk about due to traumatic experiences which may have contributed to a conscious decision not to speak about it. Equally, for the second question, the amount people described their current dream life varied depending, for example, on DPDR severity and medication which influenced the type and amount of dreams had. These factors

made certain experiences of more importance, sometimes shifting the focus of narratives away from dream experiences towards waking ones.

While all narratives described experiences of the self over time, responses were not typical of a beginning-middle-end structure, chronologically from childhood to adulthood. This may be for several reasons. Sometimes participants struggled to access memories for past feelings or events, and for some, memories from various time points in their lives were prompted naturally as conversation progressed. For others, difficult or traumatic histories relevant to shaping identity were shared only rapport had been built. Another reason is that none of the narratives contained endings. That is to say, at the time of the interviews, participants were still in the midst of dealing with DPDR and no one considered themselves fully recovered. Finally, this structure may result in part due to FANIM, which encourages participants to share memories and thoughts as they come to mind rather than chronologically. This adds to the earlier discussion of what constitutes a narrative and supports the idea that chronicity is not a necessary feature and perhaps the lack of this is in itself insightful into one's story.

3.4.2 Narrative Types

The three narrative types proposed by Bamberg (2012) used as listening devices during analysis were present in all participants' stories. These served as the main ways in which identity was experienced and made sense of. Within each narrative type, stories were organised into subthemes (table 6).

Table 6

Narrative Types and Subthemes

Narrative Types	**Subthemes**
Constancy and change across time	*"I no longer remember what it feels like to be me": Loss of pre-DPDR self and attempts to reconcile with the present*
	"I've never felt like I belong": Similarity between pre and post-DPDR sense of self
Intersubjectivity	*"What is 'Normal'?": Faking a sense of self and doing what is expected*
	"It makes you feel so much less crazy": Interpersonal situations which strengthen or weaken sense of self
Agency	*"There's a ceiling that I cannot just go beyond": Taking control vs feeling powerless*
	"Something I wished I could do in real life": Waking life as scary and dreams as a safe space to regain agency

Though each narrative type featured heavily in all participants' stories, they differed in some ways to Bamberg's (2012) original description. Thus, his theoretical framework necessitated adaptation to encapsulate participants' experiences. Given the limited existing research in this area, this allows for a novel methodological contribution. Adaptations are explained below.

Narratives of constancy and change across time tended to fit Bamberg's (2012) description of trying to integrate a past and present self into a coherent whole. Bamberg (2012) suggested these narratives would not focus on whether one has changed or how, but on how such change is navigated. However, participants' stories demonstrated the converse as they spent considerable time making sense of how they had changed rather than how this change was navigated. This could be partly due to the nature of DPDR in causing a clear divide

between life before and after its onset, as well as the interview questions which explicitly asked participants to compare their sense of self before and after DPDR.

In narratives about sameness vs difference, Bamberg (2012) stated individuals align themselves with or differentiate from others based on shared values, morals or principles. However, this aspect of identity did not reflect narratives told by participants which instead focussed on the subjective experience of identity as shaped by external pressures and interpersonal dynamics. Specifically, participants reflected on the dissonance between presenting a socially acceptable version of themselves and their inner sense of who they truly are or should be. Additionally, narratives emphasised how external validation or rejection either strengthened or undermined their sense of self. Thus, while there remains a social dimension to how identity is shaped, this narrative type was re-named "intersubjectivity" to better capture the narratives' relational and contextual nature.

In narratives about agency, participants did reference bodily agency, as described by Bamberg (2012), however other forms of agency were also identified such as having control over ones thoughts, environment, emotions, future or behaviours. Whether people felt grounded or powerless to the effects of DPDR was considered to align with and expand on Bamberg's original idea of a 'victim' vs 'high agency' role. This is compared in waking and dreaming experiences.

The remainder of this chapter explores the three narrative types and their corresponding subthemes using quotes to exemplify them. At times, lengthier excerpts are included. This avoids stories being de-contextualised and offers readers additional information to enhance their understanding and felt sense of participants' experiences. Furthermore, it offers readers the opportunity to evaluate the researcher's argument independently (Reissman & Quinney, 2005). Finally, during phase six of analysis, Fraser (2004) described short-listing certain stories for analysis and suggested providing readers the criteria used to do this may help them reflect

on the logic underpinning the analysis. In order to represent all experiences fairly, all participants are quoted. However, longer excerpts were chosen if:

a) They demonstrated a narrative type/subtheme through the words used.
b) The interview led to sufficient information about additional context which the researcher could reflect on, in-keeping with the FANIM approach which pays considerable attention to the role of the researcher in the relationship and wider context.

Constancy and Change Across Time

This narrative type includes two subthemes which capture the ways participants felt their identity had changed or stayed the same over time. First, the subtheme *Loss of pre-DPDR self and attempts to reconcile with the present* contains the story told by almost every participant of how aspects of their identity had been lost because of DPDR. The subtheme *Similarity between pre and post-DPDR self* reflects the ways in which, notwithstanding these changes, some participants noted similarities between their experiences of self before and after DPDR.

Stories in this narrative type were characterised by unfinished, trailing sentences, stammering, stuttering and self-interruption. These disjointed communication styles are thought to reflect the underlying uncertainty and pain experienced as participants attempted to make sense of their stories aloud, often for the first time, both for themselves and the researcher.

'I no longer remember what it feels like to be me': Loss of pre-DPDR self and attempts to reconcile with the present

Almost every participant spoke about how their sense of self had changed since developing DPDR. Generally, changes were seen as negative. Serena and Elliot self-reported

to be the youngest to have developed DPDR, with Elliot identifying this be to age 10 and Serena age three. As a result, neither could recall a sense of self before DPDR.

> *Serena*: "I almost have grown up with it, so it has almost always kind of been me, if that makes sense".

> *Elliot*: "That's that's actually hard because I was about 10 years old when I first got my symptoms of derealisation, I think depersonalization was a bit later, but, so I, I don't actually remember what it feels like not to have this".

Others struggled to describe a pre-DPDR identity because it was something they were "unaware" of (Nathan).

> *Daniel*: "I I I don't think it was questioned really, it, it's just, you exist, right?".

> *Lucas*: "I was kind of flowing with things and activities and I was never questioning my sense of self back then. Like it was a normal, perhaps natural, implicit way of living, you know?"

For those who could recall a pre-DPDR sense of self, personality changes were framed as being "damaged" (Kai) due to a loss of some positive attribute. For example, Leo characterised his pre-DPDR self as "spontaneous", "confident" and "capable", having previously found it "easy" to talk and "connect" with people. His experience of social interactions being difficult was shared universally. For Kai, experiencing social connection as "richly" as he once did was hailed as "like winning the lottery".

There were differences as to whether personality changes were gradual or sudden. Nathan and Daniel both used the metaphor of a light switch to describe this but differed in their experiences. Nathan, who has experienced DP for 16 years, said: "It wasn't like a lot of people

have it where it's like a sudden flicking of a switch or they wake up with it and it's just there and it's intense and terrifying. It was very much a slow sort of creeping in like a, like a dimmer switch. Like, being sort of turned down slowly and it, and it still kind of gets worse. Even now". In contrast, Daniel described the change in his personality as "two completely different people really, in that, because it was, it was sudden. Umm, like a light switch. There was, you know, there is a very clear 'the former me' and 'the secondary me' I suppose". This secondary version, in his words, had to be "synthesised" and "rebuilt." Others referred to the loss of their former self as an intense sense of "grief" (Leo, Elliot). This term was striking as it expressed the sharp distinction and disconnection between the two selves, whilst evoking a felt sense of sadness at the profound impact of that separation, implying a part of them had died.

While 'self' was a difficult concept to define, many made reference to the self being a "collection of memories" (Kai), and it transpired that as well as experiencing changes to personality traits, participants often felt they had lost a sense of their former self because they either lacked a coherent timeline for personal memories or felt emotionally detached from them. For example, Nina observed: "Somehow the DPDR is sort of, one of the things that it felt or feels like is kind of being consumed by the present moment", resulting in an inability to feel "any ownership of one's past or personal history". The quotes from Nina and Daniel both contain examples of self-correction regarding past and present tense when speaking about their self or DPDR – "it felt or feels" (Nina), "there was, you know, there is" (Daniel). This was not uncommon in other interviews and such sentence structures may indicate the confusion participants felt about reconciling the past and present into a coherent whole.

Despite being able to recall past memories, Kai felt unable to connect to them emotionally. His self-interruption and stutters are characteristic of the way narratives in this theme were told, and indicate the difficulty he has with integrating his past and present sense of self:

> "I mean, yeah, I feel the person I am now feels like somebody who has only lived for 10 years. The reason why that is, is because it feels like, that the person- no, sorry, uhh yeah, it almost feels like as if the person before that was a different man, so it feels like that whole, [stutters] it feels like I have, like this insight into someone else's life. You know, I'm, I'm sort of the new…. because I've almost forgot what it is like to be the guy I was. I don't. I no longer remember what it feels like to be me".

Leo's experience underscored this, referring to his memories of the past as "factual information" which was "distant and vague". Like Kai, he struggled to articulate the impact on his sense of self:

> "Umm. Yeah, I think the main thing is like being connected to my memories. Like now it just feels quite foggy, like… yeah, I'm not really sure how else to describe it. It's like they're faded and you can't really fully grasp… you can't really… you just can't really connect to it in a sense. That's like, you know, you know, you know what happened. You know those things happened. But yeah, like there's no, like, you're not really able to grasp, grasp it in your mind. Yeah, there's not really any emotion there".

In this detailed excerpt below, Elliot's emotional turmoil is unmistakable as he describes the difficulty he has integrating his past and present self, due to a profound difficulty in his perception of continuity of time:

> *Elliot*: "But in terms of experience of myself in the world that's missing, I I I. I have a lot of trouble with the sense of time and history. So I mean, I look out my window here and my reaction is that where's this? How did I get here? Because I I I literally experience that I'm 23, which is before the depersonalization got worse. I mean, I grew up with it, but it got worse. So my brain is literally giving me the experience of, well, that's not familiar. It should be...36 years have gone and it's exhausting".
>
> Interviewer**: "**Yeah. So it sounds like in your mind, you're still thinking from a 23 year old's point of view from how you were back then".

> Elliot: "Emotional experiences back then, my thinking is, is…you know my thinking has sort of analytically progressed, but it's, in terms of familiarity and experience. I'm really...I don't understand how I got here".
>
> Interviewer: "Yeah. What happened at 23?"
>
> Elliot: "I drove myself to try and finish a degree and in the days afterwards, just literally in the days afterwards, my mind sort of seized up in this sort of obsessive shock and I just couldn't get out of it and it just cycled with depersonalization and I'm still in it, so…and that's how my brain has just preserved that time, as it were. That hasn't progressed in, in, in experience. I mean I've grown up, but it hasn't registered as emotional history".

Linked to this, Elliot described a recurring dream in which he returns to university at his current age, only to find he is "too old to be there" and the "world as he knew is gone". He considered this dream a sign that "perhaps time *has* passed".

> *Interviewer***:** "How how does having that type of dream impact your sense of self upon waking up? Your sense of identity and your symptoms?"
>
> *Elliot***: "**Now that one is very painful, it's it's um it, it's shocking to my sense of self because I'm having to accept that this dream is showing me that it's true, that it's gone, that time. So my sense of self experience is grief. It doesn't help me, it doesn't help me feel that I am my age now in Bristol. I've got somehow in Bristol. So it, it shocks my sense of self because I haven't got that continuum of experience through time. So the dream shocks, the dream shocks my sense of self, yes".

Elliot's narrative stood out due to the stark loss of time perception he experienced whilst retaining such a vivid memory of his former self, both of which were extremely pronounced in comparison to other participants. This created significant cognitive dissonance and distress as

he struggled to reconcile his current and past experiences into a coherent whole. His account is characteristic of Frank's (1995) 'chaos narrative', a type of storytelling where life events are experienced as overwhelmingly disjointed, without a clear resolution or understanding. In a chaos narrative, the storyteller is unable to construct a coherent or linear sense of their experience, often reflecting a sense of loss, confusion, and powerlessness. This is evident in the fragmented speech and repetition of the word "shock", which is reflective of Elliot's internal chaotic experience.

During the interview, Elliot often broke eye contact, furrowed his brow and placed his hand on his head, visibly grappling with the intensity of his feelings. He frequently interrupted himself—"It's. It's. In waking life" and "So I'm, it's terribly painful"—which, combined with his nervous gestures, drew the listener into his internal struggle as he seemed to be searching for ways to make sense of his narrative for both himself and the researcher. His stuttering and hesitations, like those of other participants, suggested speaking these thoughts aloud was a new and challenging experience. This interview was the first time Elliot had been asked to compare his former and current self, perhaps adding to his uncertainty about how to articulate the complex emotions involved. To soften the conversation, the researcher noticed a degree of mirroring some of his hesitations, repeating phrases like "how how does...".

"I've never felt like I belong": Similarity between pre and post-DPDR sense of self

Although every participant noted changes in their sense of self as a result of DPDR, some spoke about the similarities between their pre and post-DPDR self. Similarly to before, this was usually described in a negative way, and narratives in this subtheme describe how for some, a sense of self has always felt "fragmented" (Nina), "not stable" (Elena) or "not whole" (Kai). For these people, DPDR did not alter their identity as profoundly as others, but rather amplified an ongoing challenge with fitting in.

The types of similarities people described varied. For Nathan, experiencing childhood bullying which spanned 13 years contributed to a feeling of not fitting in pre-DPDR: “even though pre-depersonalisation I wasn't a happy person at all, and I'm still largely not, I don't think I kind of knew who I was”. Leo also struggled to describe a pre-DPDR sense of self: “I guess if someone asked me before even like, oh, what, how would you describe yourself? I think I’d probably struggle”. Leo, Dominic and River (they/them) all described themselves as “introverted” before and after DPDR. Having grown up with undiagnosed ADHD, River recalled: “I just felt more like things were overwhelming already, so I wasn't a very loud kid”. Finally, Serena described herself as “emotionless” both as a child and currently. However, similarities were not only character-based, as Wilana explained that as a child, she felt she was in the “wrong body”, and that due to her “tomboy” interests, she “should have been born a boy”. She added: “And nobody told me anything about puberty…so there was this sort of dissociation *then* cause I didn’t know what's going on”.

Other narratives revealed how traumatic upbringings led to an unstable or “vague” sense of self (Elena), with a continued experience before and after DPDR of finding it difficult to “connect” to other people:

> *Elena*: “My first years of life were really traumatic, so that's probably set you, set you in a not really stable path in your life. Trying to figure out the world and yourself and and the adults that are probably you know, unstable themself to to, to for you to, to get grounded”.

English was not Elena’s first language and upon emigrating to the UK, she described how work-place bullying further weakened her sense of belonging. This theme of cultural trauma was not in isolation and Nina’s narrative conveyed a similar sentiment. Having never experienced “a firm ground to build a strong sense of identity on”, Nina was born in Japan to

a Chilean mother and American father. They lived in Sudan before emigrating to the UK. She described her upbringing as "traumatic", the impact of which was a difficulty distinguishing a "clear before and after [DPDR] sense of self" and led her to question if "the strong sense of self as other people experience" ever developed at all.

> She reflected: "I think this kind of lack of a cultural and geographic identity was one factor in me feeling like not very grounded and connected to location or like, I guess not having the same sort of shared cultural references as other people that's got a quite a disconnecting experience".

Nina's fragmented sense of self before and after DPDR is reflected in her artwork which expresses key themes of her identity. She commented: "I just felt like my work over the years was like so fragmented. It was like I had to re-invent what I wanted to do each time". Nina's story drew many parallels with Kai, whose interview provided the name for this theme. Kai felt his sense of self was "never strong" as a result of his mixed heritage. He described his former self as "confused", "sensitive" and "introspective"; aspects of his personality he felt had never changed. He explained:

> "Belonging to a group or a kind of, you know, 'am I this or am I that?' you know, ethnicity or whatever identity it is, you know, like if you're, if you want to, if I wanted to belong to like White English group or a Moroccan group or a black group or Asian group or whatever and I've never felt like I belong in any of them. So there's that as well. So I don't really have any of that. And then I never was one of these people that dressed in a way that you know, like I've always never fitted into sort of people's groups of…social groups either. So um, yeah".

Kai's narrative of his self being othered came to life not just through his description of events, but also his engagement in the interview. He often reiterated that if you had not experienced DPDR, "you wouldn't get it". At times, this meant his sentences were unfinished

as he seemed to stop himself from fully explaining his thoughts. This created an impression that perhaps he felt there lacked a purpose in explaining his experiences because the researcher, who has not experienced DPDR, would not understand them. Further to this, I wondered how my position as a white female may have influenced this interaction, especially as Kai identified "White English" as a group in which he was othered from. Owing to this dynamic, the interview lacked a flow and sense of shared understanding which felt present in other interviews. His minimal eye contact and multitasking throughout the interview—such as doing household chores—compounded this and suggested a detachment from the interaction. Nonetheless, as a result, Kai's interview provides both an experiential insight into how his sense of self is experienced as other, and a felt sense of how this might be reinforced or re-enacted through interactions with others.

Commonly, having an unstable sense of self was reflected in people's dreams. For Kai, themes of betrayal permeated his dreams which he felt symbolised his "deep fear and insecurity" of being "left out" or "deserted". Elena had dreams in which she was floating away from her body, creating a sense of "not being grounded in reality". Nina and Wilana recounted dreams in which they were a different person entirely, physically or as someone who had a different job. For Serena, waking difficulties in experiencing emotions were mirrored in her dreams. She commented: "there is a feeling. It's just I'm- I don't know what they are or I can't describe it".

Intersubjectivity

This narrative type explores intra- and interpersonal processes involved in participants making sense of their identity in relation to others. The first subtheme, *Faking a sense of self and doing what is expected* explores participants' internal thought processes as they attempt to make sense of societal norms and to portray a version of themselves which adheres to this.

The second subtheme, *Interpersonal situations which strengthen or weaken sense of self* explores how acceptance or rejection from others influenced their sense of self, with experiences of belonging reinforcing their identity, while feelings of alienation or exclusion led to self-doubt and a weakened sense of self.

"What is 'Normal'?": Faking a sense of self and doing what is expected

As highlighted previously, participants experienced changing and unstable identities. Not only was instability caused by traumatic childhood experiences or difficulties connecting to memories and a sense of time, but also by the pressure to conform to societal norms and expectations. A common experience emerged of "going through the motions" of daily life, only to later question whether their behaviours and interests were a genuine reflection of themselves or an attempt to fit into society.

Nathan's excerpt depicts this internal struggle, as he questions the authenticity of the interests which form his identity, and whether they are the by-product of following social norms or something he chose:

> "I don't know if I even have an identity anymore. I'm just doing what I've been told to do and what I've fallen into, and I'm just mindlessly going through the motions of things and yeah, it was kind of a scary thing to sort of step back and look at things and go 'Why am I doing that?' You know? I know I've always done that. I've done that for the last five years. But *why?* is that something I *want* to do? Is that something I have to do? Have I chosen to do this? Is it an interest? Are my hobbies even my hobbies anymore? Am I just doing things because that's what I do and am I actually getting anything out of it? All those sorts of like, very reflective thought processes and um yeah I think last year especially was very much a realisation that my sense of self and my identity of who I am and it's really slipped, but because I've been distracting and just like being more productive, being more productive, the symptoms have carried on worsening in the background and I'd been kind of pushing through them and pretending I couldn't

> see it, and I think inevitably you get to a crossover point where your abilities and your commitments just come so far apart. You just explode".

With a lack of full stops and pauses, Nathan's communication style throughout the interview consistently conveyed a sense of urgency and provided an insight into his state of mind. His thoughts overflowed with questions, spilling into a stream of consciousness that revealed the myriad uncertainties he faces and the intensity of his introspection regarding his identity.

Participants' self-scrutiny over their identity in relation to social norms seemed to intensify in interactions with others. Elliot described "treating language like maths" and shared: "I try and logically present who I am through, I call it 'the algorithm' where I will gesture or use it to contrive an expression, so I put into this shell who I really am to show you and others. But it's, it's automated". Despite Elliot's interpretation of his communication being contrived and meticulously presented, this did not translate in the interview, which felt disjointed and fragmented, as described in the first subtheme regarding his loss of sense of time. Adding to this, Dominic said:

> "If I don't really spend a lot of energy to try to connect, I may not actually come out as- it may not- I'll come out as somebody maybe absent minded or somebody whose mind is not there, so I have to spend a lot of energy trying to connect what's in my mind and trying to connect to the conversation with engagement and at the end of it all I come out very tired".

This act of presenting a curated version of oneself in public is referred to by Goffman (1959) as impression management. His theory likens this act to that of theatre play, with the true version of ourselves only being presented "backstage" in the privacy of our own homes. The metaphor of "roleplaying" or "performing" was used by some suggesting not only do their

actions feel artificial, but that there are socially accepted ways to enact certain "roles." Wilana captured this struggle when she reflected, "I remember once I asked myself if I was a performer...and by that I mean I used to be confused as to who I really was and who I presented myself to be to survive. So it was a nightmare." Similarly, Serena said: "I almost feel like I'm trying to be that role and I suppose within trying to be that role, it was kind of like, well, surely if you're- if that's the role you're playing at the moment, you *are* that."

In contrast to Dominic and James, both Wilana and Serena express that altering their behaviour to "fit in" leads to genuine confusion about their identities. For Serena, the act of "faking a sense of self" was "not conscious," unlike Dominic and Elliot, for whom the performance felt more deliberate. Serena emphasises that this was not merely a mask to be removed in private; rather, an identity struggle that permeated her daily life. She illustrates this further by discussing her role as a mother, from which she feels disconnected. Her remark, "It was just something you did" highlights the societal norms and expectations imposed on women her age. Serena continued: "Now like, now I've got five children. I don't think, again, I think that's just kind of happened because I haven't processed from the first [child] and I'm still kind of getting used to it myself. When people sort of say 'I don't know how you do it', I'm thinking I don't know either!". Serena and Wilana's experiences bring into question whether – as Goffman hypothesised – there is a disconnection between their authentic selves and the personas they feel compelled to adopt, or rather, if there is no sense of self being hidden, as this fundamentally does not feel like it exists.

However, unlike every other narrative which questioned normality and conveyed a sense of distress at not being able to achieve this, Serena's narrative was the only one which contained a conflicting sentiment and reluctance to fit into what society or mental health professionals define as "normal."

She explained:

> "I suppose it didn't really affect me until it then got to a point where people then were asking me the questions about it and then that's then, where I suppose it become a problem. But even at the time, that wasn't really a problem for *me*, if that makes, as I think it was like mental health professionals is what I'm trying to say. For them it was them questioning me on things that…that this is like, this isn't norm- like that again that word 'normal'. This is- I don't understand. Why is it a problem?"

The subtheme's title originates from Serena's interview, which repeatedly returned to the unresolved question "What is normal?". Her persistent engagement with this topic indicates a struggle with being labelled as "not normal". Concurrently, this was juxtaposed with the expressed desire to reject the notion of normality, with Serena adding: "It's good for people to be different because that's why we have all these variations of stuff. It'd be boring if we were all the same. So if that's a good thing then why is any of this bad?"

Having lived with DPDR since infancy, for Serena, the concept of being told she is not "normal" is perplexing, especially compared to those who had a clearer understanding or memory of what normal was to them before DPDR. Thus, to be faced with the societal judgement that she is "not normal" puts into question her entire life experience, and the only self she has ever known or experienced. Additionally, throughout her interview, Serena indicated a pattern of response among her family and partner to "ignore" difficult experiences "as if they never happened". Thus, to question her identity may go against a coping style that she has always used. Unlike other narratives that describe a sense of suffering due to DPDR, Serena's narrative did not convey this same distress. As described in the first subtheme, Serena often reiterated her inability to "feel emotions," a detachment that seemed to shield her from the impact of DPDR. This indifference to DPDR symptoms ultimately shaped a narrative where the external pressures to conform to societal standards of normalcy became her primary source of discomfort, rather than the DPDR symptoms themselves.

"It makes you feel so much less crazy": Interpersonal situations which strengthen or weaken sense of self

Within narratives exploring the concept of normality, participants explored interactions with others in which they either felt able to express their true selves or not. This often depended on others' understanding and acceptance of DPDR.

Feeling misunderstood by family and mental health professionals was a common experience. For some, this impacted whether they felt they could truly be themselves. Kai felt people were "sick of hearing" about his experience of DPDR and had stopped talking about it with family entirely. Dominic's narrative was particularly notable due to the extent to which he felt forced to mask his symptoms around family, stating the people closest to him "don't know exactly what I've gone through". Dominic's interview described the impact of DPDR on feeling "not himself", "disconnected", as though he were "in a dream". Dominic remarked these words are the same as those he used to describe his sense of self to his parents and doctors 20 years ago. He shared: "But no one…they just felt that this is not something that is possible", indicating a belief from others that what Dominic was experiencing was not real. 20 years ago, Dominic made the decision to fake being well.

> "For them, they, they think up to now that I, I got well and it's not- it's no longer a problem but that's not the case and I decided I'm not going to tell them. So when I'm engaging them, I have to use a lot of energy to- so that they don't see that aspect of of me".

These narratives show how being misunderstood by others, particularly family or medical professionals whom participants' expected would be most supportive and knowledgeable about DPDR had negative consequences for their sense of self. It created an environment where they felt unable to express themselves, and in Dominic's case, forced him to actively mask his symptoms and create a persona of being recovered.

Conversely, some narratives highlighted experiences where participants felt comfortable expressing their true selves in the presence of others, specifically if they belonged to groups or professions that had a shared understanding of DPDR. Such environments fostered openness, encouraging people to share their experiences and affirming that their sense of self is 'normal'. This ultimately cultivated a sense of belonging. For example, River spoke about their experience in a DPDR treatment clinic. River's experience provided the title for this subtheme. Hearing other people's experiences and sharing their own, they commented: "It makes you feel like, like going to this clinic and like having this be a normal topic, like talking to people and they say, 'yeah, I know what you feel and it makes sense that this is connected to, like existential dread or like this and that'. And it makes you feel so much less crazy! That was really good for me". Similarly, Daniel's narrative reflected a journey of "self-empowerment" through his work with a DPDR charity where sharing his experiences served to "strengthen" aspects of his personality such as "resilience".

However, while for the majority having a sense of understanding from others affirmed their sense of self, the opposite was true for Wilana, who cultivated a strong sense of self despite a lack of understanding from her community. In her narrative, Wilana emphasised her role as a self-advocate within the Nigerian community where the topic of mental health is stigmatised or overlooked. She stated, "From speaking to a lot of people in my community, like Nigerians, a lot of us have childhood trauma that's not dealt with. There's a lot of us and we just kind of carry on and do what we're supposed to do and I'm one of the few people that talk about it. Like I bang on about it". Adopting this advocacy role, Wilana referred to herself as always having been the "black sheep". Yet she went on to define her identity with confidence:

> "I am a human being. The end. And then secondly, I'm a, I'm a woman. And then thirdly, I'm many things before I'm a Nigerian in my mind. So that's just how I've managed to get up, because if I keep holding on to that identity of culture, Nigeria,

> there's so many things I wouldn't do. There's so many things I do now that my friends are like, you know, 'you're not a normal Nigerian', but what the hell does that even mean?"

Wilana's narrative stood out not only because of its content but for the way it was told. Her use of short, assertive sentences conveyed confidence and conviction, and contrasted the hesitancy of other participants who questioned their identities and often stammered or stuttered. Despite using the word "we", her narrative reveals a difficulty in being accepted by other women in her community for whom she advocates. Acknowledging this, Wilana recognises that while her Nigerian heritage is a significant part of who she is, it should not limit her actions or aspirations: "So culture, as important as it is, I use it when it serves me. When it doesn't serve me, when I think it's wrong, I challenge it. So I don't…this culture thing is not a big thing for me. Not anymore".

Wilana reflects on aspects of her identity which are captured by the concept of intersectionality. Intersectionality acknowledges that social categories such as race, gender and class, create overlapping systems of disadvantage. Intersectionality uniquely shapes how people perceive themselves and navigate identity within different contexts (Crenshaw, 1991). As the only woman of an ethnic minority in this study, it is important to acknowledge how my identity as a white woman may have interacted with this and played a role in shaping Wilana's narrative.

Wilana's interview unfolded within a broader cultural context where black women have historically been stereotyped as either strong or angry; tropes that oversimplify their identities and lived experiences (Ashley, 2013). An awareness of these stereotypes could have consciously or even unconsciously influenced how Wilana presented her identity and narrative. For example, aligning with the positively-connotated strong black woman ideal, Wilana may have felt a need to communicate her story in a way that highlighted her resistance to being

defined by either Nigerian cultural expectations or the mental health struggles associated with DPDR. Culturally, this includes the expectation to suppress personal struggles. Her statement "I'm many things before I'm a Nigerian" reflects this resistance and strength as she prioritises her individual identity over the collective cultural identity. Furthermore, Wilana used humour throughout her interview which may have served to humanise her experiences and challenge the angry black woman stereotype. It follows that humour and self-education are common forms of 'resistance coping strategies' used by black women (Luney, 2022). Thus, her emphasis on having a strong identity and confident tone may reflect a (sub)conscious effort to bridge the gap between our different cultural backgrounds and lived experiences, ensuring that I understood her as someone who transcends any reductive or stereotypical narratives and allowing her to maintain agency over her sense of self. Affirming this hypothesis, Hooks (1989) refers to the act of storytelling as "talking back"—a means of resisting oppressive systems that endanger wellbeing and reclaiming agency through open discussions of coping strategies.

Agency

The third and final narrative type is agency; defined here as having physical control over one's bodily movements and thoughts, behaviours and future. Generally, stories described how having agency strengthened a sense of self, however participants varied as to whether agency was something they had the power to regain or not. This is captured in the first subtheme *Taking control vs feeling powerless*.

Participants also explored how their sense of agency differed in dreaming compared to waking life. This is captured by the subtheme *Waking life as scary and dreams as a safe space*. Dreams either contained a self which mirrored waking DPDR symptoms and uncertainty about their identity, or served as a way through which they experienced a sense of self free from the effects of DPDR and high in agency.

"There's a ceiling that I cannot just go beyond": Taking control vs feeling powerless

DPDR was spoken about in all narratives as something which initially people could not control. This was captured by Daniel's description of DPDR as "a weird game of chess where you're being moved into the wrong places on purpose, making the wrong decisions". What distinguished narratives in this theme was whether in reaction to losing agency, people either positioned themselves in a low agency/victim role, unable to change their circumstances, or high agency role (Bamberg, 2012), rejecting the label of victim and actively practising ways of regaining agency.

Those who identified as the former described feeling victim to their experiences and environment which was perceived as unpredictable and uncontrollable: "I don't know when it's suddenly...I don't feel it coming on. It's not like something that I can go 'Oh, this is a sign'" (Serena). They perpetually doubted their capabilities, perception of reality, choices and control over their actions and future. Most narratives contained some description of aligning with this role and a struggle to move away from it. For example, Dominic conveyed a sense of powerlessness to achieve what he feels he *should* be able to academically:

> "I feel on one side I'm very much able to do things that I should do or things that are expected of me but on the other hand, I feel it's like I cannot reach out to what I'm, what I'm supposed to do or…this, this, there is that feeling that I cannot really go beyond, even if I feel so much I have the abilities, there's a ceiling that I cannot just go beyond it".

Feeling unable to change their circumstances, many spoke about an acceptance that things will not change. For some, this seemed to bring a sense of peace:

> *Daniel*: “It became a point where it was like this is it, that whole thing of acceptance and it's like ‘this is you now’, you know? and that, I think that's part of the healing process with this condition”.
>
> *Leo*: “It's quite isolating I'd say but I'm very used to it now. It's like at the beginning, it's just like grief, basically but then you just have to, you just have to accept it. There's nothing you can really do”.
>
> *Wilana*: “I've also just accepted that it would take as long as it takes because I used to be like OK, if I take the sertraline for X number of years or months, as I thought back then, and if I'm in therapy for X number of months, everything will be fine. But I've now realised that that's not going to be the case and it took a long time to accept it. I was angry for a long time when I knew that that wasn't going to be the case, but now I'm like, ‘ok’”.

Dominic explained that for the past 10 years life had “come to a standstill” and he had been “waiting for something to happen” so that he could “start living”. His narrative provided a sense that DPDR was something he was being subjected to, but could not take action to change. Despite this, he still had “hope” things may change, outside of his control. For others, there was a sense of sadness in accepting they cannot change or rid themselves of their DPDR. Elliot’s narrative provided a strong sense of aligning to the victim role, using words such as “powerful” to describe the nature of DPDR that had “destroyed his sense of self”. Furthermore, Elliot’s understanding that he was “predisposed” to DPDR adds to the idea that he had no choice in whether it was part of his life. He shared: “I was never short of confidence or ambition or ability, but it I can't get past this DPDR barrier to do anything with this existence…but I *know* my abilities and oh, and now I'm getting older. I'm, I'm in a lot of pain from losing career or even feeling I'm in the world. It's terrible”. Elliot’s story transmitted a deep sense of sorrow as he held his face in his hands, furrowed his brow and broke eye contact.

Yet alignment with either high or low agency roles was not static, as demonstrated by Daniel, who shared his journey of DPDR and regaining a sense of agency, having initially felt he was at a "dead end with the condition", he reflected on his process of "rebuilding" a sense of self and his realisation that "Maybe there is no other option. You either do that or you just, you know, fade away or top yourself or whatever. […] later on there was a point where I was like this is…I'm not letting this get to me anymore. I'm gonna take control of it'". For some, regaining a sense of agency or control came through practicing grounding techniques, self-education or creative expression. This was experienced as empowering and a way of regaining "ownership" over themselves (River, Nina).

One commonly cited method of regaining agency was practicing grounding and mindfulness techniques. By noticing things in their environment they could see, hear, smell and touch, River came to the realisation that rather than feeling "completely passive", "my body is reacting to the environment and I *can* practise things like mindfulness or like remembering dreams". Having previously not recognised herself in the mirror, Wilana used mindfulness to connect to a sense of physical agency and belonging in her body, taking time to examine parts of her body and name them, such as the texture of her skin, or the placement of moles and scars. Other ways she grounded herself was to take notice of her environment, having previously worn sunglasses she explained: "it's almost like I'm trying to get things as drab as possible in real life to match how I feel but then I'm now learning to counter that, like 'No. No, this is part of your grounding' Like, 'Come on open your eyes'".

Wilana and Daniel both explained how DPDR enabled them to "take risks". Daniel said that he felt his personality was "stronger": "I'm well, just like the kind of resilient, mental resilience, I suppose…and kind of ability to kind of…I don't know take risks, I suppose, and to do things I want to do and like actually take on responsibility and you know, do things like working for the charity rather than, you know…it's kind of like being part of what's going on

rather than being on the sidelines just worrying about it or. Yeah, it just all that stuff really kind of empowerment, self-empowerment". Daniel spoke about this in reference to his work at a DPDR charity who are currently filming a documentary about the disorder. Similar to the advocacy which Wilana spoke about in the Nigerian community, it seemed learning about DPDR and sharing this with others was an important way to regain a sense of purpose, fulfilment and ultimately a sense of agency.

Another way of sharing knowledge and experience about DPDR was through public artwork. River referred to this as "empowering" and explained how this creative outlet is an integral way to "regain" their voice. They explained:

> "Getting a space to be vocal is very important. So the whole idea of my the project I'm doing at the moment is like making the room scream because I myself have been needing to scream for very long but that's very scary. Like I'm too shy to just go on a stage and scream but you can use the frequencies like if you point the microphone at the speaker, then it picks up the same frequency again and then it will scream".

"Something I wished I could do in real life": Waking life as scary and dreams as a safe space to regain agency

This final subtheme explores how agency is experienced in dreams. It describes how some participants found the world "scary"; a place where traumas happened, where one can be judged or mistreated by others. As explored earlier, these traumatic experiences created a fragmented and unstable sense of self which lacked agency in the world. Dreams either mirrored this low-agency self, or offered a place of safety where people could regain agency by feeling their emotions without fearing the consequences, control their surroundings, physically leave a situation if they wanted to and re-enact traumatic experiences in ways not possible in waking life.

Many narratives highlighted a sense of feeling overwhelmed in reaction to being fully present in the world. For Elena and Lucas, this related to feeling their emotions which both described as "overpowering". Both experienced their dreaming self as one who lacked physical agency making it difficult to distinguish from their waking self. To describe this, Lucas recounted a dream in which his body was "empty, like with no organs", which created a sense of "not being inside of my essence not being inside myself". Since no longer experiencing DPDR symptoms in waking life, he no longer experiences these dreams.

The idea of feeling overwhelmed by having waking agency was also felt by River, for whom agency was overshadowed by a fear of "being perceived". River recounted a particularly vivid mindfulness exercise, in which the sensory clarity they gained was both illuminating and unsettling:

> *River*: That was one of the moments where really like, where it cleared up for me and it was like the colours seemed more bright and like the speech that is usually like mumbled, everything just like came together kind of. And then it also, like, I was in the middle of it. Like it felt like it was like things were suddenly more 3D, but that was also a bit scary because I mean, there's a reason why my body, like, shuts out some of these things, right? Because it was at some point in my life just a bit heavy to carry everything. I know that I'm there because I react to things around me and people react to me. But then sometimes it's very scary when people react to me because it does also remind me that I am there and like I will say or do things that do have consequences.
>
> *Interviewer*: hmm
>
> *River*: And then when I… Yeah, I don't know. It's also about like being perceived. I think that I, I told my dad once when we were talking about this like, this non-binary thing, like I think it's about wishing not to be perceived because it's so intimidating to be perceived for like your presence in the space and I think this fear is also rooted in

> my dissociation a little bit because if I, if I don't perceive myself, it feels very out of control that other people perceive me. And that's very scary. Maybe, maybe…"

River makes clear that they understand DPDR to function as a protective mechanism, and made links in their interview to experiences of sexual abuse and their gender identity which contribute to a conscious desire to *lack* agency; to "be loved and be seen" without being "observed too closely". River's fear of being perceived or judged by others was echoed by Elliot. Like River, he understood his lack of agency in waking and dreaming life to serve to protect his sense of self:

> *Elliot*: "My disorder still protects me from feelings, even in the dream. So if I had a positive dream or about me being well, that would potentially make it, it will be like subverting depersonalization, and it [the disorder] doesn't- It insists it will not be so. I think there's a probably a sense if I, if I, if something, if a good feeling got through in real life or in a dream, then I would find that threatening because 'oh the shell would be going!', the protection would be going and how would I cope with feeling? and even as, even if you say that I can feel this 'Oh hang on, I feel a bit seen?' because the possibility of it changing, it's, it's really powerful this DP. Well perhaps… that's my interpretation".

Elliot's experience of dreams as an area where his emotional guard might slip was contrastingly spoken about as both a threat to his self-protection but also a relief. Rarely, he also experienced dreams in which he *did* regain agency, with these dreams seeming to offer a space to feel his emotions "more strongly" and free from the judgement of others. He hypothesised: "It's [waking life] more threatening because people *are* really there. They are really looking at me and then in the dream I probably know they're not" and later "because I know it's just imaginary and a dream and so it's safe to have a body feeling".

This experience of dreams as offering emotional safety was shared by Wilana, though her embrace of this agency stood in opposition to Elliot. For all other participants, reliving traumatic experiences through their dreams was spoken about as an experience in which the lack of agency felt at the time of the waking trauma was mirrored in their dreams. However, Wilana was uniquely able to re-live traumatic events in her dreams whilst exercising control that she did not have at the time of the trauma.

> "If the dream is me reliving something, then I know what's gonna happen. Sometimes I don't. Sometimes it's the first time I'm (clears throat) excuse me, I'm properly going through something and I'm like, 'oh ok'. Like, it happened recently where there, I knew there was an event that happened in my childhood, but it was only in the dream that I actually was able to walk through the actual details that I'd never walked through before. So I was like 'ah, ok', and there's a kind of safety that comes with being in the dream cause somehow I know I'm in a dream, but is also very, very real. Like it's in colour. You know, so… cause when the dreams don't really mean anything, they're black and white.

In the previous subtheme, Wilana's avoidance of sensory agency in waking life was discussed – an experience shared by others. Thus, her embrace of sensory experiences in dreams, particularly within the context of re-living traumatic events, signifies the powerful and therapeutic role of dreams which offer a protective realm where she can safely reprocess past traumas and engage with her senses in ways that may feel too overwhelming in waking life.

Other participants also found dreams offered a space to exercise control and reconnect with aspects of themselves inaccessible in waking life. This experience of feeling grounded and empowered in dreams marked a significant departure from their waking reality, where DPDR limited their agency and emotional expression. For instance, Dominic – a PhD student – described his joy at being able to run mathematical simulations in his dreams. To "engage

his mind" and obtain a result provided him with a sense of mental and emotional connection that he longed for in waking life: "It's a great feeling and it's something that I always wish for. If there is something that I can get back, just one thing, it's just that sense of connection".

In the first narrative type, participants commonly described their pre-DPDR self as someone who lived implicitly and for some, dreams were a place where they felt reconnected to this former version of themselves and exercised agency in the form of being able act naturally, with their actions flowing from inherent desires and values. Nina explained: "Maybe in the dream like one just isn't questioning it. You're just getting on with whatever you're doing in the dream and then in waking life, there's more of a reflection of, how real does this feel? That, that questioning isn't going on in the dream". Leo echoed this in his account of reconnecting to his pre-DPDR sense of self who he characterised as "spontaneous" in his dreams. He reflected: "I think in my dreams I'm more like spontaneous like, like I said, how in my waking life like I've lost that spontaneity. Probably in my dreams there's a bit more of that" adding "that's a kind of authenticity". For Leo, these dreams included scenes with familiar people and places—a common experience among participants when describing moments of reconnecting with a former sense of self in their dreams.

Finally, almost half of participants regained a physical agency and "control" through flying dreams. This was experienced as "empowering" (Nina) and further interpreted by Wilana as meaning "being able take off in my dream and leave a situation that wasn't serving me was something I wished I could do in real life, but I couldn't".

Discussion

4.1 Chapter Summary

This final chapter critically considers the results presented. Findings are discussed in relation to relevant existing literature and strengths and limitations of the research are considered in light of the researchers personal reflections. Practical, theoretical and clinical implications are discussed, upon which suggestions for future research are made.

4.2 Results Summary

This thesis is the first study to qualitatively explore the experiences of identity in people with DPDR in waking and dreaming life. As an under-researched condition, studies on DPDR are largely quantitative. While qualitative studies have begun to investigate lived experiences, only one study has ever focussed specifically on identity (Fino et al., 2024).

Twelve in-depth interviews were conducted with individuals with lived experience of DPDR, aimed at exploring their experience of identity/sense of self in waking and dreaming life. Guided by Bamberg's (2012) theory of identity, narrative analysis revealed stories could be conceptualised into three narrative types: narratives about constancy and change across time, intersubjectivity and agency. Each narrative type contained two subthemes.

Most interviews contained all three narrative types. However, at times it was possible to identify certain narrative types as more pertinent to guiding an individual's story and that this differed between participants. Narratives are an ongoing process of construction, shaped by the pragmatic interaction of the interview and participants' immediate interest in self-exploration, assertion and self-presentation (Lucius-Hoene, 2000). Thus, stories about oneself can change depending on the context; who one is speaking to or through the language choices made, creating new connections, stories and versions of the self (Loots et al., 2013). Therefore, narrative types should not be understood as capturing the historical reality of participants, but

as capturing that individual's experience at that particular point in time. It is proposed that the narrative types found by this study contribute to narrative theory, theories of identity and dreaming, to the literature on lived experiences of DPDR, and clinical practice, which will now be considered.

4.3 Narrative Type and Subtheme Findings

Constancy and Change Across Time

Loss of pre-DPDR self and attempts to reconcile with the present

Within this narrative type, the first subtheme highlighted several findings. First, the importance of memory in forming a coherent identity was emphasised, and that a weak or emotionally detached memory for the past contributed significantly to a self that felt fragmented in the present. Second, changes to personality were often seen as negative and likened to "grief", with participants referring to themselves as "broken" or "damaged". Finally, the way these narratives were told strongly aligned with Frank's (1995) 'chaos' narrative.

According to some theorists, autobiographical memory is so intrinsically linked to identity that it is considered a part of the self (Robinson & Hawpe, 1986) and the role of memories in providing a stable 'self-system' has been widely researched (Conway & Pleydell-Pearce, 2000). Stability in identity comes from being able to rely on having an internal repertoire of thoughts, feelings and actions, such as personal attributes or desires upon which we base our behaviour and ascribe meanings to situations (Markus & Kitayama, 1991). As well as guiding our actions in the present, long-term memory of events act as a guide for future behaviour, for example, re-experiencing or remembering past events helps predict what action to take, based on how it made you feel or how others responded (Hyland et al., 2023). Finally,

recalling significant life events or people acts as landmarks throughout one's life, thus, memory is key to providing a sense of grounding, continuity and stability.

Memory provides narrative continuity to identity not only across time but also across contexts (McLean & Syed, 2015) and a sense of continuity and consistent self-identity is a core psychological goal of humans (Mischler, 1999). Thus, the extent to which people can establish a sense of continuity is strongly related to a sense of wellbeing (Beike & Landoll, 2000). Yet, as demonstrated in the interviews, people with DPDR struggled greatly to recall their former self or past events. As a result, many described their current self as an entirely new identity to be "reinvented", yet they lacked the confidence in how to rebuild this self, having no references from past behaviours as to how to act or think, especially in social situations. Of note, most participants developed DPDR between the ages of 10-20; a time widely acknowledged as critical in identity development (Erikson, 1950). For the general population, memories from this age tend to relate to themes of identity and identity confusion (Conway & Holmes, 2004). Consequently, the absence of these formative memories likely exacerbated participants' current struggles with identity, leaving them without the foundational experiences typically used to navigate and affirm a sense of self.

Interviews also highlighted that several participants felt emotionally detached from their memories, as though they were factual events but which did not evoke a feeling in response. However, emotional engagement with memories is critical for constructing identity. Research supports this, showing that purpose and meaning in life are derived from the ability to craft coherent autobiographical narratives that explicitly connect experiences to identity, such as how one's past has influenced actions, thoughts and behaviours, which strongly relies on an emotional connection to the memory (Vanden Poel & Hermans, 2019; Waters & Fivush, 2015). For participants in this study, the lack of emotional connection to their memories

fundamentally disrupted this process, leaving them unable to build a coherent and meaningful sense of self (Markus & Kitayama, 1991).

The sense of loss evoked from feeling disconnected from one's self before DPDR was for many so profound, that it was likened to a sense of grief. Akin to this, one of the main impacts of grief is recognised as experiencing "a loss, diminution or disruption of *who* one is" (Ratcliffe & Byrne, 2022, p320) and much of the research on grief experiences align with the descriptions from participants' interviews, even if the term grief was not used. Particularly the following description by Ratcliffe and Byrne (2022): "During grief, one is not just unable to anticipate who one will be. One may also find that one's current sense of self is profoundly eroded; one is neither who one was nor who one will be. Norms and significant possibilities that would ordinarily constrain or even specify patterns of thought and activity are lacking. There is no fact of the matter concerning what is to be done next, how to continue" (p324). Just as with grief, narratives described an experience of being catapulted into a world lacking in established norms which would otherwise guide thought and behaviour.

Almost all narratives in this theme echoed the descriptions of Frank's (1995) 'chaos' narrative, supporting the literature on illness and grief which also fit this narrative type (Titus & De Sousa, 2011). Narratives of chaos are characterised by broken eye contact and trailing or stuttering speech. There is no future horizon that helps establish hope. Stories are disjointed and there is no progression of beginning, middle, end – only an eternal now (Lucius-Hoene et al., 2018). This way of communicating was observed in many and exemplified by Elliot's story which strongly lacked a linear sense of time. Chaos narratives draw the listener in and immerses them in feelings of hopelessness and demoralisation yet are the types of narratives which psychoanalyst Reik (1948) argues clinicians should pay attention to. Reik (1948) draws attention to the meaning that can be found behind embodied communication including gestures,

eye contact and rhythm of voice, emphasising that one should not shy from a train of thought that might seem senseless and absurd.

Similarity between pre and post-DPDR sense of self

The second subtheme highlighted that for some, a sense of self has always felt fragmented, unstable or not whole. DPDR amplified pre-existing difficulties some participants had with feeling that they belong or fit in. Various factors contributed to participants feeling they did not have a strong identity before DPDR including bullying, childhood trauma of racial, sexual and physical abuse or moving country at a young age.

These experiences are known in the literature as adverse childhood experiences (ACE's), defined as "highly stressful, and potentially traumatic, events or situations that occur during childhood and/or adolescence. They can be a single event, or prolonged threats to, and breaches of, the young person's safety, security, trust or bodily integrity" (Young Minds, 2018). Studies have consistently demonstrated that experiencing ACE's increases the chances of developing mental health difficulties including anxiety, depression, PTSD and dissociation (Briere & Rickards, 2007). Neurologically, ACE's have been found to reduce modulation in parts of the brain including the amygdala and hippocampus, involved in memory, affect and executive functioning (Lupien et al., 2018), which corresponds to the difficulties in memory and emotion discussed above. Furthermore, ACE's can disrupt the development of self (Briere & Rickards, 2007; Cederbaum et al., 2020), by disrupting one's ability to mentalise, which is the ability to make sense of one's own thoughts, feelings and behaviours (Wagner-Skacel et al., 2022).

Of note in this theme was the impact of culture. Nina and Kai both came from mixed-heritage backgrounds, which included traditionally collectivist and individualistic cultures. Nina, with a mix of Japanese (collectivist), American (individualist) and Chilean culture (a mix

of the two; Benavides & Hur, 2020), and Kai, a mix of Moroccan (collectivist) and British (individualist) culture. Their narratives described difficulties navigating opposing cultures, each with conflicting norms and expectations which ultimately impacted their development of a coherent self-concept. Underscoring this, studies have found that heightened cultural identity conflict correlates with poorer self-concept clarity, lower self-esteem and increased psychological distress (Rahim et al., 2021). Furthermore, dissociation is more commonly found in individualistic cultures (Seedat et al., 2003), and correlates with experiences of overt racial discrimination, particularly verbal slurs and derogatory comments (De Maynard, 2010). However, it should be noted that these correlations are of dissociation generally rather than DPDR specifically, and were conducted in African American minority groups. Due to the lack of research in this area, no other studies of ethnic minorities are available, however the narratives in this study suggest the findings may be applicable among other cultures, though further research is warranted.

Intersubjectivity

This narrative type was the only concept of Bamberg's (2012) to be re-named, as it was felt participants' stories did not reflect the original narrative type of 'sameness vs difference'. Rather than speaking about aligning with or differentiating from social groups based on morals and values, stories emphasised how external validation or rejection from others either strengthened or undermined their sense of self. They also reflected on the dissonance between presenting a socially acceptable version of themselves and their inner sense of who they truly are or should be. Thus, while there remains a relational and societal element, these narratives were better captured by the title *intersubjectivity*.

Faking a sense of self and doing what is expected

Narratives in this subtheme were concerned with questioning what "normal" ways of speaking, acting and behaving are. They demonstrated how participants questioned and in some cases modified their behaviour fit in with this.

To be accepted by others and perceived as normal by social standards, participants often likened themselves to a "performer"; someone wearing a mask, carefully contriving their actions. Yet acting this role only increased their sense of detachment as they questioned whether their actions and beliefs were a true reflection of their own desires or society's expectations. These narratives therefore provided an experiential insight into the statement from Horney (1951). Though originally intended to describe people with neurosis, Horney's (1951) description fittingly captures the experience of those with DPDR, stating: "he aims to feel what he should feel, wish what he should wish and like what he should like. In other words, the tyranny of the should drives him frantically to be something different from what he is or could be...that his real self fades" (p159). Of interest, this sense of performing was not felt by the researcher during interviews. Perhaps honestly disclosing and directly recognising such acts including as they arose in the interview served as a way to remove their mask. Though they might still have 'performed', I have no reference of their 'true' self in a private setting to compare to. It is also possible that certain performed behaviours went unnoticed, as I may have perceived them as socially normative, such as greetings, small talk, smiling, or maintaining eye contact.

The concept of wearing a mask is a widely accepted behaviour among society in general. Psychoanalyst Winnicott asserts that everyone develops two parts of the self during infanthood and coined them the 'true self' and 'false self' (Winnicott, 1960). The true self refers to being authentic and present in one's mind and body, while the false self is an imitation or mask where the expectations of others may override inherent desires or way of being, yet is

adaptive in certain environments. It has since been asserted that dissociative disorders may be considered a symptom of false self syndrome, whereby one's true self is blocked from expression (Phillips & Frederick, 1995) because at one time it was required or forced that these aspects of the self be denied (Winnicott, 1945). Similarly, Goffman (1963) added that concealing one's appearance or behaviour is especially done by people who are stigmatised to protect their identity and pass as "normal". Yet, he explains that the discrepancy between who one actually is and the roles or expectations placed onto them by society only creates more anxiety and marginalisation or exclusion. This, he stated, "has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world" (Goffman, 1963, p19). Considering the experience of ACE's discussed previously, it could be conceived that perhaps being one's true self could have resulted in further bullying or harm, and so detaching from this and reality was protective. The idea of stigmatisation was discussed in several interviews, with participants feeling their friends or family would not understand or accept that their experiences are valid, for example Dominic, Kai and Wilana, whose family all originated from cultures outside of the UK where DPDR is less accepted or understood. While this theory suggests a sense of conscious decision-making in wearing a 'mask', some participants eluded that the lines between these two selves became blurred, feeling "confused" as to who they "really" are compared to who they "presented themselves to be to survive" (Wilana), or that if one plays a role, "you *are* that" (Serena).

Again, the role of culture appears important. In trying to fit in, narratives in this theme placed an emphasis on autonomy, a defining trait of individualistic cultures, such as to be "productive", find hobbies or being a mother. Studies have found that in individualistic cultures, an inability to achieve these results in feelings of alienation and loneliness, rather than shame which is most predominantly experienced in collectivist cultures (Draguns & Tanaka, 2003). In line with this, Sierra et al. (2006) found differences in the prevalence of DP across

the UK, Columbia and Spain, with lower scores in Colombia – a collectivist culture. They hypothesised this difference may be due to societal influences on how the self is constructed. Similarly in Japan, DPDR rates of just 9-25% in people with panic disorder (Mizobe et al., 1992) may suggest belonging to an individualistic culture may increase one's vulnerability to distress by feelings of alienation and separateness and ultimately DPDR (Doherty, 2014).

Interpersonal situations which strengthen or weaken sense of self

In the second subtheme, the idea of wearing a mask was explored further, and revealed the role that others play in whether aspects of one's self are safe to express. For example, feeling misunderstood by mental health professionals and family led Dominic and Kai to avoid showing others aspects of their suffering, though this required considerable effort to monitor and modify their behaviour around others and led to increased isolation. Similarly, research supports that masking in those with mental health difficulties can have detrimental consequences on depression, anxiety and feeling disconnected from one's true sense of identity (Miller et al., 2021). The finding that some participants felt misunderstood by mental health professionals is sadly unsurprising given the literature cited in the introduction.

Some participants felt the need to mask symptoms due to fear of stigmatisation from others. The role of stigmatisation is significant because if internalised, it can lead to 'self-stigma' where negative beliefs about oneself or their condition are believed and held by the person themselves (Fung et al., 2023). Research has found a positive correlation between self-stigma and dissociative symptoms in people with bipolar (De Filippis et al., 2022), and in people with DPDR who lacked support from others (Fino et al., 2024). Further evidence of the internalised stigma in people with dissociative disorders comes from Fung et al. (2021), who found 66.7% felt they were worse than others and 47.2% felt ashamed to have mental health problems. Self-stigma may pose an additional barrier to help-seeking in people with

dissociative disorders (Nester et al., 2022) and is associated with PTSD symptoms, suggesting that it may also contribute to the maintenance of psychological disorders (Schröder et al., 2021).

While those who felt misunderstood by others or the need to mask their symptoms experienced a weakened sense of identity, others spoke about ways their identity was strengthened through the acceptance and belonging that groups for people with DPDR offered, such as the *Unreal* charity support group. In support of these findings, Fino et al. (2024) found that isolation was a crucial aspect of understanding the struggle with building a coherent, distinctive and continuous sense of self. Their study underscored the importance of social support from family, partners and friends, which mitigated the negative impact of identifying as someone living with DPDR. Receiving support reduced the extent to which people with DPDR perceived the condition to disrupt their lives, thereby enhancing their sense of agency and well-being and ability to find meaning and purpose in life. Support included other people having an awareness of participants' struggles with DPDR as well as a contemporaneous empathetic, non-judgmental and lenient acceptance of it.

While there are no empirical studies of the benefits of therapeutic groups or peer support for people with DPDR, there are for dissociative disorders more broadly, including a study by Holbæk and Vrabel (2024). They conducted a 20-week psycho-educative group therapy for people with dissociative disorders which participants felt helped in: understanding their symptoms, developing a language to describe it, feeling less confused, feeling a more coherent sense of self, realising they are not alone and feeling affirmed that their experiences are real and valid by seeing their struggle from another perspective and recognising it in others. Many reported not feeling so "crazy" – strikingly, the title of this theme (*"It makes you feel so much less crazy"),* a quote from River's interview as they described the positive impact of group-based mindfulness. Other interviews in this study highlighted the empowerment and

validation felt as a result of sharing their experiences in groups or hearing the experiences of others.

While there is no group therapy for DPDR, studies are currently investigating the efficacy of Trauma-focused mentalization-based treatment (TF-MBT; Smits et al., 2024), a group intervention designed to treat PTSD and specifically target dissociation symptoms (Rüfenacht et al., 2023). The group has been found to help create a safe space to learn from others in similar situations, thereby reducing feelings of isolation and promoting new coping strategies and insights. One explanation as to why group work may be of such importance to people with DPDR is its implications for how people view their identity. Chan et al. (2018) found that in people with a range of mental health difficulties, group therapy increased a sense of group identification, which in turn was associated with reduced self-stigma, higher levels of empowerment and better clinical recovery outcomes, such as reduced anxiety and depression. In the case of DPDR, where a fragmented identity is at the core of its symptoms and the risk of self-stigma is high, the results of these studies and the narratives in this subtheme suggest that group identification may be of significant importance when discerning possible treatment approaches.

Agency

Taking control vs feeling powerless

In this final narrative type, identity was discussed in relation to the sense of agency people felt in their waking and dreaming life. Agency is first discussed in relation to waking life.

Research studies and autobiographical accounts emphasise agency as a central aspect of DPDR which impacts one's narrative identity (Fino et al., 2024; Perkins, 2021). In this study, agency was said to be gained through advocacy, self-education, art work and practicing

grounding techniques, and resulted in a sense of control physically and mentally, as participants felt an increased sense of hope that they do not have to be victim to the effects of DPDR. Similarly, Fino et al. (2024) view agency in DPDR to encompass the sense of ownership, empowerment and achievement, as well as one's beliefs in the ability to influence the course of their own and others' lives through their actions.

Like the narratives in this study, physical health research from Hydén (2008) led him to note the striking pattern for narrators to depict their illness from two opposing views: the perspective of an ill person and a healthy person, with narrators vacillating between the two, often within the same narrative. Hydén (2008) viewed this as a depiction of narrators' struggle to define how their illness narrative is to end, much like the participants in this study, none of whom considered themselves to be recovered. This type of storytelling is encapsulated by Good and Good's (1994) 'subjunctive narrative', which refers to illness stories which contain elements of hope as well as hopelessness, which both arise as a person attempts to follow a story and make sense of an illness which has its own inexorable course and rhythm (Good & Good, 1994). It is the vacillation between the two positions which characterises them and sets them apart from narratives of chaos (Frank, 1995), in which no hope can be found.

First to be considered are narratives describing low agency. Rüfenacht et al. (2023) suggest that the addition of PTSD or trauma may increase the likelihood of individuals with dissociation categorising themselves as having low agency because re-living traumatic events can exacerbate dissociation by heightening confusion and disorientation, leading to intense feelings of defeat and powerlessness. These feelings can create a sense of being trapped, with no escape from emotional pain or hope of recovery. In illness research powerlessness is associated with a *loss* of self (Charmaz, 1995). However, in the current study, not all people who experienced trauma characterised themselves as low agency. For instance, while Nathan and Kai who felt traumatised by their experiences of bullying categorised themselves as having

low agency, others including River and Wilana who experienced sexual or physical abuse reported a high sense of agency.

One explanation for this could be the impact of belonging to a group or community. As discussed previously, people with mental health difficulties who belong to groups or communities have access to greater coping resources (Chan, 2018), a collective identity which protects against self-stigma, an increased sense of empowerment, and are less likely to feel hopeless (Rüsch et al., 2009). They may therefore feel able to reclaim a positive sense of self and find purpose despite their struggles (Chan, 2018). In the current study, participants who categorised themselves as having high agency were often part of a community. For example, Daniel and Wilana felt empowered by sharing knowledge and supporting others within a charity or church. Similarly, Rüsch et al. (2009) found people with mental illness who strongly identified with their community were more likely to engage in public education and support others with similar challenges. Overall, communion has been found to be extremely important in people with DPDR (Fino et al., 2024), and refers to the quality of interpersonal connections, including group affiliations, which help individuals cope with adversity, feel supported, and reduce isolation or loneliness. Without communion, people with DPDR reported significant loneliness as DPDR symptoms drive them to withdraw from others. This raises the question of whether group identification could ameliorate low self-identification and act as a moderating factor in the relationship between trauma and low sense of agency in people who dissociate. However, as experiences of trauma were not explicitly asked about in the current study, this hypothesis cannot be definitively tested.

One of the main ways participants reported regaining agency was through grounding exercises, a technique recognised as crucial for managing dissociative symptoms by patients themselves (Jacobson et al., 2015) and various treatment approaches (Lanius et al., 2014). Treatments which prioritise this include TF-MBT and sensorimotor psychotherapy, which

explain that allowing oneself to feel present in one's body in a safe environment helps foster a sense of safety and mitigate helplessness (Lanius et al., 2014). Though definitions of 'agency' and 'self' differ within the literature, the physical body is often referenced as a cornerstone of both and physical agency is seen as the fundamental base and anchor for sense of self (Damasio, 1994). Various hierarchical models such as Damasio (1994) and Kearney and Lanius (2022) explain how bodily feelings and sensations evoke thoughts, emotions and memories, thus directly influence our sense of self, how we regulate our feelings, direct our attention and guide our actions (Kearney & Lanius, 2022). Therefore, if this is sensory-level of memory encoding is disrupted, it makes sense that this could also disrupt recalling the full emotional context of experiences, leading one to feeling detached from memories (Kearney & Lanius, 2022) as was evidenced in the first subtheme. It suggests that grounding techniques may therefore have positive cascading effects to reconnecting with higher forms of affective and embodied self.

Waking life as scary and dreams as a safe space to regain agency

In this final subtheme, agency was discussed in relation to dreams. Due to the experience of trauma or ACE's, many developed a view of the world as a "scary" place in which bad things happened or in which they now lacked agency due to DPDR. For some, this lack of agency was mirrored in their dreams, while for others, dreams served as a safe space where agency could be exercised despite their waking inability to do so.

That dreams tend to reflect waking life experiences is a well demonstrated phenomenon known as the continuity hypothesis (Schredl, 2006), and is particularly evidenced in dreams reflecting waking-life concerns and stressors (Solomonova et al., 2021). For example, a 10-year longitudinal study found higher levels of waking anxiety correlated with dreams reflecting aggression, negative emotions, failures and misfortune (Pesant & Zadra, 2005). Theories as to why this is vary, though one of the main and widely accepted explanations is that dreams reflect

our brains process of consolidating memories of waking-life experiences (Malinowski & Horton, 2015). It is therefore unsurprising that many participants in the current study dreamt of their self as lacking in agency in their dreams. However, what is striking, is that some people felt able to exercise control and agency in their dreams though this starkly contrasted their waking life. One theory which may explain this is the emotion regulation theory of dreaming (Cartwright et al., 2006) which is supported by psychotherapists (Hartmann, 1995) and posits that dreams provide a safe space to process negative emotions from waking life. However, research supporting this theory is lacking and instead continually finds that dreams tend to be negatively biased (Malinowski & Horton, 2015; Zhang et al., 2024). Thus, there is little evidence to support why people in this study who experience distress in waking life still dream positively, of a self who is high in agency and free of DPDR.

Though the healing power of dreams has been studied, a recent review into the function of dreaming only cited this in relation to lucid dreams (Krishnan, 2021) in which people can make conscious decisions to influence the dream narrative (Sackwild & Stumbrys, 2021). Only one participant in this study reported the ability to do so. Wilana felt connected to her former self, before DPDR developed, though this was the time she experienced abuse. In her dreams, she could re-live the traumatic events knowing that she was safe and in a dream and was able to manipulate the scene. Likewise, qualitative research has found that in those with PTSD and depression, lucid dreaming provided dreamers with a sense of empowerment, as they could re-visit traumatic events with a sense of safety and control (Sackwild & Stumbrys, 2021).

For those who in the current study did not have lucid dreams but dreamt of themselves as well, this included being able to socialise confidently with others, dreams of flying, or carrying out work which in reality felt confusing and difficult due to DPDR. According to psychoanalytic theory, the incongruence between who one is in waking life, and who one desires to be is often dramatically depicted in dreams (Ellis, 2013). LeBaron et al. (2001)

suggest this is because dreams attempt to compensate for the stressful aspects of illness, while Freud's (1899) theory on the wish-fulfilment of dreams suggests that dreams represent and fulfil one's unconscious desires, thoughts, and motivations that the conscious mind suppresses or represses. While participants expressed a desire to be free of DPDR, their narratives also revealed underlying fears of living fully present in the world. For instance, River described feeling "intimidated" and thought it "scary" to be perceived by others in waking life, explaining, "there's a reason why my body, like, shuts out some of these things, right? Because it was at some point in my life just a bit heavy to carry everything." Similarly, Elliot stated, "my disorder protects me…how would I cope with feeling?". These reflections suggest a protective mechanism that mirrors repression—where the desire to recover may be unconsciously held back due to fears of being overwhelmed. For those with DPDR, dreams may serve as a safe psychological space where their wish to feel fully present or reconnect with a former sense of self is fulfilled. Thus, dreams provide temporary access to a state they consciously desire but may unconsciously fear.

Research into dreams in those with dissociative disorders is lacking greatly. To date, studies support that higher CDS (Gwyther et al., 2024) or DES (Cheung, 2012) scores of dissociation are associated with higher frequency of nightmares, thus the finding that participants experienced positive dreams in which they retrieved an authentic and healed sense of self is novel and argues against the continuity hypothesis. Similarly, research of dreams in people with illness is also scarce, with no peer reviewed studies finding evidence of positive dreams in ill patients. Only one book could be found to support this experience, written by McGillicuddy (2013) on his two year experience working with terminally ill people as a Chaplain and Pastoral Counsellor. He reported that the most commonly shared dream was seeing oneself fully healed from illness, and similar to the participants in this study, such dreams evoked both a great sense of joy and hopelessness that they might never achieve this.

In discerning the factors which contribute to positive and negative dreams in healthy people, Sikka et al. (2018) found that peace of mind was associated with positive dreams, suggesting that despite experiencing waking stress, having an acceptance of the negative experiences and contentment despite fear or sadness led to positive dreams. Interestingly, in the current study, all of the participants who described "accepting" DPDR, that there is nothing they can do to change it, all experienced positive dreams. Yet some who did not describe this acceptance, such as Nina, still also reported some positive dreams. Regardless of whether dreams are positive of negative, exploring the themes which arise and how they may represent parts of the self has been shown to be a valuable therapeutic intervention for individuals with DPDR, aiding in understanding their identity (Heaton et al., 1998) and focusing on the relations among dissociation, sense of self, sleep and dreaming are recognised as a priority for future research (Van Heugten-Van Der Kloet & Lynn, 2020).

4.4 Researcher Reflections

Throughout this process, I have reflected on my ever-changing development as a researcher and clinician, and how this dual role influenced the research process. Within this, I considered my personal biases and preconceptions and how I can use the knowledge gained from conducting this research as a soon-to-be qualified clinical psychologist. The benefits and limitations of my position and skills as a researcher are reflected upon here.

Aligned with the epistemological stance of this research and my personal values, I acknowledged my responsibility in authentically representing participants' experiences. Initially, I was conflicted about which method of analysis to use. I considered Thematic Analysis (Braun & Clarke, 2006), however, I felt narrative analysis offered the opportunity to reflect on why and how something was said to better paint a picture of the narrator, their mannerisms and engagement with the process. I wanted the reader to "experience the

experience" of the narrator (Ellis & Bochner, 1992, p98) rather than provide factual descriptions of participants' demographics and quotes devoid of their context, which would not capture this.

Initially, when choosing stories to present, I noticed I favoured well-expanded quotes over those in which people struggled to articulate their thoughts. However, the process of narrative analysis forced me to consider *why* people may have struggled to articulate their thoughts. What was it about their condition or the dynamic between us that influenced their tone of voice, what they shared, the way their sentences were structured? What did this evoke in me in response? Perhaps if I had used thematic analysis I would not have realised this bias and these voices would have been silenced. Reflecting on the interviews which felt difficult because answers were unelaborated shifted my focus from myself to the participants and our dynamic. Furthermore, rather than focussing on my skills as a researcher alone, narrative analysis constantly reminded me that this was a co-created piece of research, and I came to understand how we both influenced the interviews. This helped me to decrease self-criticism and increase empathy for the participants, fostering a more balanced understanding of our shared contributions.

Simultaneously, I became increasingly aware of how my position as the researcher may have detracted from the interview focus at times. Representing an NHS professional, I inadvertently became a figure to whom participants could voice their frustrations in the absence of other professionals. This became particularly apparent in interviews where participants shared the long and difficult journeys endured to receive a diagnosis, often recounting stories of being misunderstood or dismissed by professionals and the deep frustration this caused. Narrative interviews with people with Alzheimer's disease led Ramanathan (1997) to observe that while repetition of the same story or story fragment can create broken narratives or temporal disruption, it may be a way for individuals to emphasise key aspects of the self—

reminding listeners of what they find most important. Thus, although at the time I felt these narratives were detracting from the focus of interviews, I later realised how they related to participants' self and incorporated this in the results.

These considerations also sparked a great amount of self-reflection in areas I had not previously considered. Both during and after interviews I noticed myself questioning areas where I previously thought I maintained neutrality. For example, I had not fully appreciated the emotional toll of receiving a dissociative disorder diagnosis or the (in)adequacy of treatment pathways. I realised my clinical experiences providing therapy to people with dissociative disorders created a false sense of confidence and understanding that I actually did not have. However, the interview process evoked a strong reaction in me as I empathised with participants' frustration for not feeling understood. As a clinician, I struggle to understand how others can witness someone in such a vulnerable position and leave them feeling abandoned and unheard.

Through journalling, I noticed how other personal biases influenced the interviews. Lucius-Hoene et al. (2018) explain that researchers naturally have a tendency to analyse interviews in a temporally linear fashion, including how the present can be understood in light of the past and looking for a plot to construct narratives into a meaningful whole. Yet stories involving illness often defy ordinary ways of story-telling, as first demonstrated by Frank's 'chaos' narrative (1995), and other subsequent researchers (Lucius-Hoene et al., 2018). Illness narratives are by nature ambiguous because they do not have a clear, foreseeable end (Good & Good, 1994; Hydén, 2008). As cited in the literature and expanded on in the themes of this research, people with DPDR experience a disruption to their temporal flow and so in hindsight the interview questions were perhaps unsuitable. Specifically, the question, "Can you describe the differences between your sense of self before experiencing DPDR and the one you currently experience?". This reflects the linear way I might conceptualise an experience – from past to

present. Though beginning with an open invitation, it implicitly encourages participants to structure their responses in this way which may not align with how they conceptualise experiences and could present significant challenges for them. This mismatch in storytelling can easily lead to 'communicative breakdowns', in which a shared understanding and meaning cannot be established, leading to either participant or researcher wanting to withdraw from the interview (Lucius-Hoene et al. 2018). Looking back, I thought of one participant in particular who struggled to answer this question and how my instinct was to compartmentalise it, asking first about their sense of self before DPDR and after. Now, however, I recognise this approach prioritised my own desire for coherence. A more effective approach might have been to simply ask what they wanted to say about their sense of self, without imposing before-and-after timestamps.

4.5 Strengths and Limitations

Limitations

One limitation these reflections highlight includes the lack of public and patient involvement (PPI), which may have helped refine the interview questions. A systematic review supports that PPI empowers service users and benefits research by improving the quality and relevance of data collected; leading to more patient-related themes being identified in the analysis (Brett et al., 2014). PPI was not sought as it is only with hindsight these realisations were had about how the wording of questions may have impacted the interview dynamic and participants' ability to answer, however it is a suggested consideration for future research. Another limitation was some participants struggled to recall dreams and many commented they would have been willing to keep a dream diary leading up the interview to reflect on. Though it was explained in the information sheet that dreams would be discussed, perhaps this is the type of suggestion PPI would have highlighted and that future research may consider.

The population in this study is both a strength and a limitation. This group are under-researched and thus to include different cultures, ages and gender, experiencing varying degrees of DPDR is a great strength given the small sample. All but two people either lived in the UK at the time of interview or had for the majority of their life. However, the sample is not large enough to be representative of all DPDR experiences or even the majority and some experiences such as help-seeking, social norms and stigma are culture-specific, which limits the generalisability of results within the DPDR community and outside of the UK.

While the researcher made every effort to remain transparent, it is impossible to eliminate all bias (Mantzoukas, 2005), and by nature, qualitative research requires a degree of subjectivity in the interpretation of results and interview process, therefore some non-verbal cues may have been missed or interpreted differently by another researcher. Future research may ensure intercoder reliability by having a research team who could separately watch and code interviews before converging (O'Connor & Joffe, 2020).

Strengths

Notwithstanding these limitations, this study has several strengths. The main strength of this research lies in its novelty, as people whose experiences are extremely underreported have been given a platform to raise awareness as to how DPDR has impacted them, and may therefore have important practical, clinical and theoretical implications.

Second, the interview and analysis methods bring numerous strengths. As discussed in the methodology, narrative analysis encourages a far deeper level of interpretation of results than other qualitative methods (Squire et al., 2013). Using a psychodynamic paradigm and drawing on factors of race, gender, culture and societal norms, results were interpreted beyond individual experiences and surface-level observations, widening readers' perspectives to social discourses which may have informed participants' experiences and the way the researcher

interpreted them. Outside of narrative approaches, the positionalities of participants are rarely considered in qualitative research, yet they influence how participants engage with researchers and the dynamic between them, meaning it is important to discuss them where possible (Joseph et al., 2021).

FANIM and narrative analysis both encourage stories to be told and presented as intact as possible. Telling stories in their entirety intensifies the process of self-reflection and auto-epistemic processes; that is, the process of reflecting on and constructing one's own knowledge or understanding of themselves (Lucius-Hoene, 2000). Furthermore, emphasis was placed on interpreting non-verbal cues. This, together with presenting longer excerpts, rendered it "possible to grasp understandings which by far exceed the means of traditional research on self-concepts" (Lucius-Hoene, 2000, p3), helping to make sense of finer-grained distinctions between individuals (Thomas et al., 2009).

Finally, published accounts of physical and mental illness tend to reflect stories of recovery or meaning made from the experience, such as Frank's (1995) narratives of 'restitution' and 'quest' at the risk of excluding voices which do not tell stories of hope and optimism (Shapiro, 2011). Narratives in this research provided an alternative insight into distressing experiences.

4.6 Implications and Recommendations

Practice

While it is challenging to recommend an overall practice suitable to all people with DPDR due to the small sample size, this study uncovered some commonalities between experiences. Therefore, various implications will be discussed. Specifically: treatment which focusses on the concept of identity and sensorimotor aspects, the use of dreams in clinical practice and the importance of destigmatisation and ways of achieving this.

Narrative Approaches to Understanding Identity

DPDR has numerous destabilising symptoms, such as distortions and disruptions to various senses and time. As demonstrated through the systematic literature review and the interviews in this research, the culminating impact of these distortions is a disruption to a coherent sense of self, which all participants in the study by Fino et al. (2024) said was "constantly threatened". The impact of not having a coherent sense of self transcends various aspects of life by impeding people's ability to bond, pursue educational or work attainments, and construct a positive and functional social identity (Fino et al., 2024).

It is therefore suggested identity be a core focus of future interventions. Corroborating this, interviews with people suffering complex dissociative disorders about their preferences for treatment by McLeod et al. (2021), found people emphasised the need to focus on repairing negative changes to identity (in addition to enhancing agency and hope that change is possible). Furthermore, anecdotally, some participants in this study discussed the unhelpful approach of therapy encouraging increased work productivity, and viewing this as a sign of clinical improvement, despite the relenting impact of DPDR on their sense of self. That people with DPDR commonly report ineffective treatments (Fino et al., 2024) suggests current approaches are not targeting the aspects of DPDR which people struggle with most. As a result, the cycle of perceptual dysregulation, anxiety, rumination and isolation that characterises DPDR are reinforced (Fino et al., 2024).

Narrative approaches are also useful in treatment, with narrative therapy models originally emerging from the post-positivist era described in the methodology chapter (Hawke et al., 2023). Various forms of narrative-based therapies exist including narrative therapy (White & Epston, 1990), narrative exposure therapy (NET), narrative enhancement and cognitive therapy (NECT; Yanos et al., 2011), and cognitive narrative psychotherapy (Gonĉcalves, 1995), among others. Though they differ in some ways, what unifies narrative

approaches is the underlying aim to explore people's identity through storytelling, thus helping them to regain a sense of control and coherence over their memories and experiences (Carey & Russell, 2003). Unlike the negative self-beliefs people with DPDR hold such as being "broken" or "damaged", narrative approaches do not view people as having an internal deficit or deficiency (Carey & Russell, 2003). Narrative therapists recognise the role language plays in constructing and/or maintaining problems, and helps people challenge or 're-author' dominant narratives that otherwise maintain the problem (France & Uhlin, 2006). Narrative approaches can complement the aims of CBT as the information from personal stories can be used to understand people's maladaptive beliefs or schemata (Hawke et al., 2023).

Studies already provide support for the use of NET and NECT in reducing dissociative symptoms in those with comorbid PTSD (Domen, 2024; Hansson et al., 2017; Mauritz et al., 2021, 2022). Furthermore, NECT – a group-based intervention – was evidenced to reduce self-stigma and improve self-esteem (Hansson et al., 2017), discussed earlier as important factors relating to regaining a stable sense of self. Narrative therapy is an inclusive approach which pays particular attention to the social, cultural, and political contexts in which stories are situated (Madigan, 2011) which the results of this study highlighted as important to understanding the unique impact of DPDR on people's identity. It is therefore recommended narrative approaches may be a highly suitable approach to exploring identity in group or individual DPDR treatment.

Use of Dreams

According to Gabel (1990), dreams are a window to understanding one's sense of self. Originating in psychoanalysis, dreamwork is central to many psychotherapeutic approaches (Roesler, 2018). Psychoanalytic schools vary in how dreamwork is undertaken, for example psychodynamic approaches may interpret and decode the meaning of a dream or symbols

within it, while Jungian methods may view the dream as a personification of a person's personality (Spangler & Sim, 2023). Nonetheless, the aim of dreamwork is to help people linguistically express somatic and symbolic experiences, ultimately offering a restored and restructured sense of self-continuity (Scalabrini et al., 2021). For dissociation, this process can help a person represent and own dissociated aspects of themselves (Diamond, 2020). While case studies of DPDR using dreamwork were not found, case studies of people with a range of other diagnoses including DID, D-PTSD, anxiety and depression support and demonstrate this process (Diamond, 2020; Paley, 1992; Roesler, 2018). For example, for those in Roesler's (2018) study, interpreting dreams contributed to breakthroughs in therapy by symbolically enacting inner conflicts which allowed clients to gradually process and integrate unconscious material. Such breakthroughs correlated with changes to clients' dreams which then depicted them as having more agency. Therefore, with both self-continuity and agency being restored and strengthened, dreamwork may be highly suitable for those with DPDR. Furthermore, Chefetz and Bromberg (2004) emphasise the importance of the relational process that takes place during dreamwork which they argue is the foundation of a person's growth in therapy, rather than the content of dreams discussed. Thus, the process of dreamwork may importantly offer relational safety which as discussed throughout this thesis, is often disrupted in those with DPDR.

Yet within clinical practice dreams are frequently ignored (Leonard & Dawson, 2018). This may be due to several reasons relating to client and therapist as clinicians may feel uncomfortable or unskilled to work with dreams and offer interpretations (Pesant & Zadra, 2004). Clients equally may avoid discussing dreams due to a fear of confronting troubling imagery or powerful emotions, for example (Heaton et al., 1998). This research supports a link between dreaming and waking experiences of identity in DPDR, with dreams potentially offering an escape or alleviation from waking symptoms, and encourages clinicians outside of

psychotherapy to be open to communicating with clients about dreams; modelling that it is both beneficial and acceptable in therapy (Hill & Knox, 2010).

Sensory-Based Interventions

As discussed in the introduction, many therapeutic recommendations for dissociative disorders stem from our understanding of trauma and mainly from the dissociative subtype of PTSD (D-PTSD), in which people with PTSD concurrently experience symptoms of dissociation including DPDR. D-PTSD is distinctly recognised in the DSM and cognitive approaches such as CBT are considered the first line of treatment (Kearney & Lanuis, 2022). However, some research has found dissociation reduces the efficacy of cognitive therapy outcomes in those with PTSD (Ehlers et al., 1998) and BPD (Kleindienst et al., 2011) and it is suggested here that somatic sensory stimulation may counter this. In these approaches, clients are encouraged to notice the presence and intensity of bodily feelings and sensations, which may bridge the gap between the brain and body which can be difficult to address in cognitive therapies alone (Kearney & Lanuis, 2022).

Supporting this, narrative interviews about the barriers and facilitators to treatment for people suffering various dissociative disorders found all participants highlighted the importance of activities involving reintegrating the senses (Hirakata, 2009). The importance of sensory-based interventions are already recognised in treating dissociative disorders, particularly the use of grounding and mindfulness techniques (Forner, 2018). The findings of this research suggests an additional benefit of sensory-based approaches is the impact it has on regaining a sense of self. Physical sensory stimulation was suggested a key aspect of regaining a sense of self, by facilitating access to emotional and autobiographical memories. This contributes to self-awareness – which has already been identified as central in establishing a sense of continuity in identity. Furthermore, it facilitates a sense of physical and mental agency

which was argued to be the basis of a sense of self. By recognising physical sensations and linking them to emotional states, people can recognise triggers of dissociation and learn to self-soothe and regulate their emotions (Rüfenacht et al., 2023). Once this is achieved, the person may be better able to participate in cognitive approaches (Fraser et al., 2017).

TF-MBT is one approach to treating dissociation which incorporates sensory-based techniques, however it is currently in its infancy. The study by Rüfenacht et al. (2023) presents the first clinical trial of TF-MBT for people who have experienced trauma and present with dissociative symptoms, including DPDR, thus further research is needed to evaluate its efficacy specifically in relation to sense of self. However, patient feedback from this initial trial reported the treatment facilitated a "deeper comprehension" of identity and emotions.

De-stigmatisation

Evidence suggests early intervention for unusual experiences improves treatment outcomes (Golay et al., 2016). However, Nester at al. (2022) conducted the first study to assess barriers to help-seeking in people with dissociative disorders across 16 countries including the UK. The majority of participants had DP (75%) or DR (71%). 96% reported barriers to accessing mental health treatment, and 92% to continuing treatment. The most common reason was stigma from providers who did not believe their symptoms were real or that they 'could not be helped', in addition to clients perceiving clinicians to lack training in dissociation and trauma. In the current study, interviews and literature highlighted the negative impacts on identity and help-seeking as a result of not being believed or supported by both medical professionals and friends or family, thus targeting the lack of understanding and potential stigmatisation by both groups is crucial.

Doctors will likely be the first person to come into contact with a person seeking help for DPDR, and the narrative told here plays an important role in determining how any

communication between the doctor and patient develops (Clark & Mishler, 1992). Stigma and misunderstanding at this stage may prevent people from engaging further with support (Gronholm et al., 2017). Therefore, it is suggested professionals seek training about DPDR and how it is distinguished from other dissociative disorders. Doctors may also play an important role in disseminating information to families of people with DPDR and how they might support them. Given the value of group support discussed, peer-support groups should be offered to those receiving a diagnosis and their families. While some are available through Unreal Charity, further provision is needed and clinician engagement with these groups could be encouraged as part of professional training. Overall, the narratives in this research may offer clinicians a way to make sense of stories about DPDR at a time when so few have been written about. It is hoped this may ultimately help professionals understand and value their experiences in a way that may improve the care provided.

Theory

Narrative

The findings of this thesis contribute to theories on narrative research as it applies to understanding dissociative disorders. First, the temporal structure of narratives highlights stories that exist in tension with conventional storytelling norms, and that this way of storytelling was most dominant. Second, findings extend the application of physical illness narrative literature to mental illness, including Frank's (1995) 'chaos narrative' and Good and Good's (1994) 'subjunctive narrative'. Future researchers may benefit from an awareness of using multiple narrative types from different authors and from the literature on physical illness, to facilitate listening to narratives with a less constrained view and thus promote better recognition of the complexity of illness experiences (France et al., 2013). Finally, in an important shift away from a biomedical paradigm of illness, the narrative lens used provides

an opportunity to represent mental illness not just as a clinical diagnosis, but as a profound experience that can be integrated and contextualised within a person's daily life, shaped by cultural, social and personal circumstances; what Early (1984) calls the 'customisation' of the illness.

Identity/Dreams

Next, this thesis contributes to theories on identity as they relate to DPDR and dreams. More broadly, this study informs the theoretical conceptualisation of identity as a construct and the interviews support the recognition of identity not as a fixed concept, but something affirmed, disconfirmed and reconfigured continually over time (Hydén, 2008).

Self-awareness is a crucial part of healthy identity development and includes an awareness of one's own emotions and bodily sensations, which interacts with autobiographical memory and provides a sense of a continuous identity across time (Hyland et al., 2023). Trauma research explains that disruption of this can lead to a sense that one's identity is broken, fragmented, "not whole" or incoherent across time, especially in dissociative disorders (Harter, 1998; Hyland et al., 2023), as it can be difficult to integrate contradictory experiences. However, the current study moves away from a trauma narrative, showing how DPDR also disrupts identity development in much the same way.

The importance of continuity in identity has been heavily emphasised in this research. Similarly, continuity underpins many researchers' and theorists' ideas about dreams, believing they serve to heal and reintegrate the self to achieve a sense of continuity when the self is threatened by dissolution or fragmented (Kohut, 1977). Overall, it has been evidenced that dream research predominantly supports the continuity hypothesis that waking experiences and symptoms shape dream content and affect. Yet both the quantitative findings from the dream diary study and subsequently the final subtheme of this research go against the notion that

dreams promote continuity in identity, as some people were alleviated from their symptoms and dreamed of a former self; highlighting stark differences to their waking life. This supports theories of dreams as a safe space and form of wish-fulfilment and brings to question what else these dreams could be heralding, such as a potential for recovery, or perhaps that these individuals have not come to terms with their new self. However currently, there is a lack of research in this area to support this novel finding.

Research

In the same way Frank (1995, 2013) suggested his illness narrative types be used as listening devices, the narrative types proposed in this thesis could be used as listening devices by researchers and clinicians working with people with DPDR. The narrative types of 'continuity across time', 'intersubjectivity' and 'agency' offer a new way of understanding and conceptualising people's experiences of DPDR, specifically as it relates to their sense of self.

Further research is needed using narrative approaches to understand the experience of DPDR for a dialogue to be created wherein patterns across studies may be compared, and from which broader narrative knowledge can be created. Specifically, this study has discussed the potential influence of culture on certain narratives, and suggests that prioritising sampling across different cultures is important so that universal and culturally specific aspects of DPDR experiences can be understood. Over time, the collective findings from various narrative studies might contribute to a model of how identity and sense of reality are disrupted in DPDR and how these disruptions are narratively reconstructed over time. Ultimately, this may strengthen the practical implications of the current study as understanding common patterns in narratives can help healthcare professionals recognise key experiences and responses in individuals with DPDR. It is also suggested studies explore more deeply the content of dreams in those with DPDR as they relate to identity, for example, by asking participants to keep a

dream diary ahead of interviews. This may facilitate participants' memory and reflections on the role of dreams.

Based on the practical implications of this work, future research could pilot and evaluate treatment recommendations, such as the need to focus on identity with an incorporation of dream interpretation and sensorimotor elements, or peer support groups on factors such as group identification, collective-esteem and self-stigma and how this relates to symptom severity of DPDR.

4.7 Conclusion

This is the first study to explore the lived experiences of people with DPDR as it relates to their dreaming and waking sense of self and the link between the two. This research has generated numerous implications and recommendations for the understanding and treatment of DPDR. First, several theoretical contributions have been made, including the function of dreams and the conceptualisation of identity. Bamberg's (2012) theory of identity was used as a listening device and adapted to explain how identity is experienced in those with DPDR. Importantly, it has shown how a disruption to a continuous sense of self is a fundamental aspect of the DPDR experience and in light of supporting research, it is suggested that focussing on reintegrating identity may have positive knock-on effects to help a person form meaningful social and interpersonal relationships and hope for the future. Additionally, autobiographical memory was found to be key to forming a stable sense of self. It was recommended that future treatment and research recognise the value of narrative and dreamwork to understanding and reintegrating a person's identity. Group work and peer support are also crucial, as well as destigmatisation among professionals and the general population. Overall, this research has contributed to a novel and important area. It provides a foundation for a holistic, person-centred

approach to understanding and treating DPDR, and has emphasised the importance of telling and publishing stories that are outside of the dominant narratives about DPDR and illness.

References

Ackner, B. (1954). Depersonalization: I. Aetiology and phenomenology. *Journal of Mental Science*, *100*(421), 838-853. https://doi.org/10.1192/bjp.100.421.838

Aksen, D. E., Polizzi, C., & Lynn, S. J. (2021). Correlates and Mediators of Dissociation: Towards a Transtheoretical Perspective. *Imagination, Cognition and Personality*, *40*(4), 372-392. https://doi.org/10.1177/0276236620956284

American Psychiatric Association. (2022). Dissociative Disorders. *Diagnostic and Statistical Manual of Mental Disorders, 5*. https://doi.org/10.1176/appi.books.9780890425787.x08_dissociative_disorders

Amiel, H. F. (1927). *Fragments d'un journal intime* [Fragments of an intimate diary] (Vol. 11, 9th ed.). Paris, France: Georges et Cie.

Andersen, P. H., & Kragh, H. (2010). Sense and sensibility: Two approaches for using existing theory in theory-building qualitative research. *Industrial marketing management*, *39*(1), 49-55. https://doi.org/10.23750/abm.v90i6-S.8640

Ashley, W. (2013). The Angry Black Woman: The Impact of Pejorative Stereotypes on Psychotherapy with Black Women. *Social Work in Public Health*, *29*(1), 27–34. https://doi.org/10.1080/19371918.2011.619449

Aydin, E., Gulluoglu, B. M., & Kuscu, K. M. (2012). A psychoanalytic qualitative study of subjective life experiences of women with breast cancer. *Journal of Research Practice, 8*(2), Article M13. Retrieved from: http://jrp.icaap.org/index.php/jrp/article/view/300/263

Baker, D., Hunter, E., Lawrence, E., Medford, N., Patel, M., Senior, C., Sierra, M., Lambert, M.V., Phillips, M.L., & David, A.S. (2003). Depersonalisation disorder: clinical

features of 204 cases. *The British Journal of Psychiatry, 182*(5), 428-433. https://doi.org/10.1192/bjp.182.5.428

Bamberg, M. (2011). Who am I? Narration and its contribution to self and identity. *Theory & Psychology*, *21*(1), 3–24. https://doi.org/10.1177/0959354309355852

Bamberg, M. (2012). Narrative practice and identity navigation. In J. A. Holstein, J. F. Gubrium (Eds.), *Narrative practice and identity navigation* (pp. 99-124). SAGE Publications, Inc., https://doi.org/10.4135/9781506335117

Beike, D. R., & Landoll, S. L. (2000). Striving for a consistent life story: Cognitive reactions to autobiographical memories. Social Cognition, 18(3), 292–318. https://doi.org/10.1521/soco.2000.18.3.292

Benavides, P., & Hur, T. (2020). Self-Construal Differences in Chile and South Korea: A Brief Report. *Psychological reports*, *123*(6), 2410–2417. https://doi.org/10.1177/0033294119868786

Benjamin, L. R., Benjamin, R., & Rind, B. (1998). The parenting experiences of mothers with dissociative disorders. *Journal of marital and family therapy*, *24*(3), 337–354. https://doi.org/10.1111/j.1752-0606.1998.tb01089.x

Bob, P. (2004). Dissociative Processes, Multiple Personality, and Dream Functions. *American Journal of Psychotherapy*, *58*(2), 139–149. https://doi.org/10.1176/appi.psychotherapy.2004.58.2.139

Boysen, G. A., & VanBergen, A. (2013). A review of published research on adult dissociative identity disorder: 2000–2010. *The Journal of Nervous and Mental Disease, 201*(1), 5-11. https://doi.org/10.1097/NMD.0b013e31827aaf81

Bradlow, P. A. (1973). Depersonalization, ego splitting, non-human fantasy and shame. *The International Journal of Psycho-analysis, 54*(4), 487–492.

Brand, B. L., & Frewen, P. (2017). Dissociation as a trauma-related phenomenon. In S. N. Gold (Ed.), *APA handbook of trauma psychology: Foundations in knowledge* (pp. 215–241). American Psychological Association. https://doi.org/10.1037/0000019-013

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brett, J., Staniszewska, S., Mockford, C., Seers, K., Herron-Marx, S., & Bayliss, H. (2014). A systematic review of the impact of patient and public involvement on service users, researchers and communities. *The Patient - Patient-Centered Outcomes Research, 7*(4), 387–395. https://doi.org/10.1007/s40271-014-0065-0

Briere, J., & Rickards, S. (2007). Self-awareness, affect regulation, and relatedness: Differential sequels of childhood versus adult victimization experiences. *The Journal of Nervous and Mental Disease, 195*(6), 497–503. https://doi.org/10.1097/NMD.0b013e31803044e2

Brown, P. (2017). Narrative: An ontology, epistemology and methodology for pro-environmental psychology research. *Energy Research & Social Science, 31,* 215-222. https://doi.org/10.1016/j.erss.2017.06.006

Buchnik-Daniely, Y., Vannikov-Lugassi, M., Shalev, H., & Soffer-Dudek, N. (2021). The path to dissociative experiences: A direct comparison of different etiological models. *Clinical Psychology & Psychotherapy*, *28*(5), 1091–1102. https://doi.org/10.1002/cpp.2559

Bustamante, N. (2023, September 7). *What is gestalt psychology? theory, principles, & examples*. Simply Psychology. https://www.simplypsychology.org/what-is-gestalt-psychology.html

Carey, M., & Russell, S. (2003). Re-authoring: Some Answers to Commonly Asked Questions. International Journal of Narrative Therapy and Community Work, *2003*(3), 60–71. https://search.informit.org/doi/10.3316/informit.652291092639962

Cartwright, R., Agargun, M. Y., Kirkby, J., & Friedman, J. K. (2006). Relation of dreams to waking concerns. Psychiatry research, 141(3), 261–270. https://doi.org/10.1016/j.psychres.2005.05.013

Cassady, M., & Baslet, G. (2023). Dissociation in patients with epilepsy and functional seizures: A narrative review of the literature. *Seizure: European Journal of Epilepsy*, *110*, 220–230. https://doi.org/10.1016/j.seizure.2023.06.020

Cederbaum, J. A., Negriff, S., & Palmer Molina, A. (2020). Child maltreatment and romantic relationships in adolescence and young adulthood: The mediating role of self-perception. *Child abuse & neglect, 109,* 104718. https://doi.org/10.1016/j.chiabu.2020.104718

Černis, E., Beierl, E., Molodynski, A., Ehlers, A., & Freeman, D. (2021). A new perspective and assessment measure for common dissociative experiences: 'Felt Sense of Anomaly'. *PloS one, 16*(2), e0247037. https://doi.org/10.1371/journal.pone.0247037

Chan, R. C. H., Mak, W. W. S., & Lam, M. Y. Y. (2018). Self-stigma and empowerment as mediating mechanisms between ingroup perceptions and recovery among people with mental illness. *Stigma and Health, 3*(3), 283–293. https://doi.org/10.1037/sah0000100

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *The Sociological Quarterly, 36*(4), 657–680. https://doi.org/10.1111/j.1533-8525.1995.tb00459.x

Charmaz, K. (2003). Grounded theory: Objectivist and constructivist methods. In N.K. Denzin & Y.S. Lincoln (Eds.), *Strategies for qualitative inquiry* (2nd ed., pp. 249–291). Thousand Oaks, CA: Sage.

Chen J., Neo P. (2019). Texting the waters: An assessment of focus groups conducted via the WhatsApp smartphone messaging application. *Methodological Innovations, 12*(3), 1–10. 10.1177/2059799119884276

Cheung, V. K. An exploratory study on the relationship between dissociation in waking life and negative contents in dreams (2012).

Cheung, V. K. L. (2012). An exploratory study on the relationship between dissociation in waking life and negative contents in dreams. *International Journal of Dream Research, 5*, 17–22. http://dx.doi.org/10.11588/ijodr.2012.1.9078

Ciaunica, A., & Charlton, J. (2018, June 21). *What can depersonalisation disorder say about the self?*. Aeon Essays. https://aeon.co/essays/what-can-depersonalisation-disorder-say-about-the-self

Ciaunica, A., Pienkos, E., Nakul, E., Madeira, L., & Farmer, H. (2021). *Anomalous self and world experiences in depersonalization traits: A qualitative study*. Preprints. http://dx.doi.org/10.31234/osf.io/vn4yz

Ciaunica, A., Pienkos, E., Nakul, E., Madeira, L., & Farmer, H. (2023). Exploration of self- and world-experiences in depersonalization traits. *Philosophical Psychology*, *36*(2), 380–412. https://doi.org/10.1080/09515089.2022.2056009

Clark, D. M., & Wells, A. (1995). A cognitive model of social phobia. In R. G. Heimberg, M. R. Liebowitz, D. A. Hope, & F. R. Schneier (Eds.), *Social phobia: Diagnosis, assessment, and treatment*, (pp. 69–93). The Guilford Press.

Clark, J. A., & Mishler, E. G. (1992) Attending patients' stories: reframing the clinical task, *Sociology of Health and Illness, 14*, 344–71. https://doi.org/10.1111/1467-9566.ep11357498

Condon, L. P., & Lynn, S. J. (2014). State and Trait Dissociation: Evaluating Convergent and Discriminant Validity. *Imagination, Cognition and Personality, 34*(1), 25-37. https://doi.org/10.2190/IC.34.1.c

Conway, M. A., & Holmes, A. (2004). Psychosocial stages and the accessibility of autobiographical memories across the life cycle. *Journal of personality*, *72*(3), 461–480. https://doi.org/10.1111/j.0022-3506.2004.00269.x

Conway, M. A., & Pleydell-Pearce, C. W. (2000). The construction of autobiographical memories in the self-memory system. *Psychological Review*, *107*(2), 261–288. https://doi.org/10.1037//0033-295x.107.2.261

Corbally, M., & O'Neill, C. S. (2014). An introduction to the biographical narrative interpretive method. *Nurse Researcher*, *21*(5), 34–39. https://doi.org/10.7748/nr.21.5.34.e1237

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, *43*(6), 1241–1299. https://doi.org/10.2307/1229039

Damasio, A. R. (1994). *Descartes' error: Emotion, reason, and the human brain*. New York: Avon Books.

Damasio, A. R. (1999). *The feeling of what happens: Body and emotion in the making of consciousness*. New York: Harcourt Brace.

De Filippis, R., Menculini, G., D'Angelo, M., Carbone, E. A., Tortorella, A., De Fazio, P., & Steardo, L., Jr (2022). Internalized-stigma and dissociative experiences in bipolar disorder. *Frontiers in psychiatry, 13*, 953621. https://doi.org/10.3389/fpsyt.2022.953621

De Maynard, V. A. (2010). The impact of 'racism' on the dissociative experiences scale. *International Journal of Culture and Mental Health*, *3*(2), 77–95. https://doi.org/10.1080/17447143.2010.488321

Diamond, M. J. (2020). Return of the Repressed: Revisiting Dissociation and the Psychoanalysis of the Traumatized Mind. *Journal of the American Psychoanalytic Association, 68*(5), 839-874. https://doi.org/10.1177/0003065120964929

Dimitrova, L., Fernando, V., Vissia, E. M., Nijenhuis, E. R. S., Draijer, N., & Reinders, A. A. T. S. (2020). Sleep, trauma, fantasy and cognition in dissociative identity disorder, post-traumatic stress disorder and healthy controls: A replication and extension study. *European Journal of Psychotraumatology, 11*(1). https://doi.org/10.1080/20008198.2019.1705599

Doherty, M. E. (2014). *More than unreal: Clinicians' practice experiences with clients affected by chronic depersonalization and derealization* [Master's thesis, Smith College, Northampton, MA]. https://scholarworks.smith.edu/theses/776

Domen, I. (2024). Narrative Exposure Therapy for PTSD and structural dissociation and Techniques for its conduct: A Case study in Japanese psychiatric hospital. *European Journal of Trauma & Dissociation*, *8*(2), 100415–100415. https://doi.org/10.1016/j.ejtd.2024.100415

Dong, T. (2023). Une étude clinique de la dépersonnalisation–déréalisation chez trois jeunes adultes drépanocytaires homozygotes du Cameroun [A clinical study of depersonalization-derealization in three young adults with homozygous sickle cell disease from Cameroon]. *L'Évolution Psychiatrique, 88*(2), 299-311. https://doi.org/10.1016/j.evopsy.2023.01.008

Draguns, J. G., & Tanaka-Matsumi, J. (2003). Assessment of psychopathology across and within cultures: Issues and findings. *Behaviour Research and Therapy, 41*(7), 755–776. https://doi.org/10.1016/S0005-7967(02)00190-0

Dugas, L. (1898). DÉPERSONNALISATION ET FAUSSE MÉMOIRE. Revue Philosophique de La France et de l'Étranger, 46, 423–425. http://www.jstor.org/stable/41076855

Early, E.A. (1984) The logic of wellbeing. Therapeutic narratives in Cairo, Egypt, *Soc Sci Med*, 19 (6), pp.1491-1497.

Ehlers, A., Clark, D. M., Dunmore, E., Jaycox, L., Meadows, E., & Foa, E. B. (1998). Predicting response to exposure treatment in PTSD: The role of mental defeat and alienation. *Journal of Traumatic Stress: Official Publication of The International Society for Traumatic Stress Studies*, *11*(3), 457-471.

Elliott, J. (2005). *Using narrative in social science research : qualitative and quantitative approaches*. Sage.

Ellis, C., & Bochner, A. (1992). *Telling and performing personal stories*. SAGE Publishing

Ellis, L. (2013). Incongruence as a doorway to deeper self-awareness using experiential focusing-oriented dreamwork. *Person-Centered & Experiential Psychotherapies*, *12*(3), 274–287. https://doi.org/10.1080/14779757.2013.836130

Ellis, L. A. (2016). Qualitative changes in recurrent PTSD nightmares after focusing-oriented dreamwork. *Dreaming, 26*(3), 185–201. https://doi.org/10.1037/drm0000031

Erdeniz, B., Tekgün, E., Menteş, Ö., Çoban, A., Bilge, S., & Serin, E. (2023). Bodily Self-Consciousness in Dreams Questionnaire (BSD-Q) and its relation to waking dissociative experiences. *Dreaming, 33*(4), 456–475. https://doi.org/10.1037/drm0000217

Esquirol, E. (1838). *Des maladies mentales : considérées sous les rapports médical, hygiénique et médico-légal* [Mental illnesses: Considered from medical, hygienic, and medico-legal perspectives] (Vol 1). Paris, France: J.-B. Baillière.

Eve, Z., Heyes, K., & Parry, S. (2023). Conceptualizing multiplicity spectrum experiences: A systematic review and thematic synthesis. *Clinical Psychology & Psychotherapy*, *31*(1). https://doi.org/10.1002/cpp.2910

Evren, C., Cınar, O., Evren, B., Ulku, M., Karabulut, V., & Umut, G. (2013). The mediator roles of trait anxiety, hostility, and impulsivity in the association between childhood trauma and dissociation in male substance-dependent inpatients. *Comprehensive Psychiatry, 54*(2), 158-166. https://doi.org/10.1016/j.comppsych.2012.06.013

Fagioli, F., Telesforo, L., Dell'Erba, A., Consolazione, M., Migliorini, V., Patanè, M., Boldrini, T., Graziani, R., Nicoletti, F., & Fiori-Nastro, P. (2015). Depersonalization: An exploratory factor analysis of the Italian version of the Cambridge Depersonalization Scale. *Comprehensive Psychiatry, 60,* 161-167. https://doi.org/10.1016/j.comppsych.2014.06.007

Fairbairn, W. R. D. (1952). *Psychoanalytic studies of personality*. London: Tavistock.

Fenichel, O. (1945). *The psychoanalytic theory of neurosis*. W W Norton & Co.

Fino, E., Jemmett-Skinner, T., Evans-Miller, R., Perkins, J., Malik, M., Robinson, M., & Webb, G. (2024). Dispositional Traits, Characteristic Adaptations, and Narrative Identity Reconstructions in Individuals with Depersonalization and Derealization. *Journal of Personality*. https://doi.org/10.1111/jopy.12976

Forner, C. (2018). What Mindfulness can learn about Dissociation and what Dissociation can learn from Mindfulness. *Journal of Trauma & Dissociation*, *20*(1), 1–15. https://doi.org/10.1080/15299732.2018.1502568

France, C. M., & Uhlin, B. D. (2006). Narrative as an outcome domain in psychosis. *Psychology and Psychotherapy: Theory, Research and Practice*, *79*(1), 53–67. https://doi.org/10.1348/147608305x41001

France, E. F., Hunt, K., Dow, C., & Wyke, S. (2013). Do men's and women's accounts of surviving a stroke conform to Frank's narrative genres?. *Qualitative health research*, *23*(12), 1649–1659. https://doi.org/10.1177/1049732313509895

Frank, A.W. (1995). *The wounded storyteller: body, illness and ethics*. Chicago: University of Chicago Press.

Frank, A.W. (2013). *The wounded storyteller: body, illness, and ethics*. Chicago: University of Chicago Press.

Fraser, H. (2004). Doing narrative research. *Qualitative Social Work*, *3*(2), 179–201. https://doi.org/10.1177/1473325004043383

Fraser, K., MacKenzie, D., & Versnel, J. (2017). Complex Trauma in Children and Youth: A Scoping Review of Sensory-Based Interventions. *Occupational Therapy in Mental Health*, *33*(3), 199–216. https://doi.org/10.1080/0164212X.2016.1265475

Freud, S. (1899). *The interpretation of dreams*. The Macmillan Company.

Freud, S. (1941). A disturbance of memory on the acropolis. *PsycEXTRA Dataset*. https://doi.org/10.1037/e417472005-593

Fuchs, T., & Van Duppen, Z. (2017). Time and Events: On the Phenomenology of Temporal Experience in Schizophrenia (Ancillary Article to EAWE Domain 2). *Psychopathology*, *50*(1), 68–74. https://doi.org/10.1159/000452768

Fung, H. W., Černis, E., & Shum, M. H. Y. (2023). Self-stigma predicts post-traumatic and depressive symptoms in traumatized individuals seeking interventions for dissociative symptoms: a preliminary investigation. *European Journal of*

Psychotraumatology, *14*(2), 2251778. https://doi.org/10.1080/20008066.2023.2251778

Fung, H. W., Chan, C., Ross, C. A., & Wang, E. K. S. (2021). Clinical features of a Chinese sample with self-reported symptoms of pathological dissociation. *Journal of Trauma & Dissociation*, *22*(3), 378–393. https://doi.org/10.1080/15299732.2020.1869651

Fury, K. S. (2023). *Does anyone else? The lived experience of writing about depersonalization on Reddit* [Doctoral dissertation, Antioch University]. Antioch University Repository and Archive. https://aura.antioch.edu/etds/984

Gabel, S. (1990). Dreams and dissociation theory: Speculations on beneficial aspects of their linkage. *Dissociation: Progress in the Dissociative Disorders, 3*(1), 38–47.

Gallagher, S. (2000). Philosophical conceptions of the self: implications for cognitive science. *Trends in Cognitive Sciences*, *4*(1), 14–21. https://doi.org/10.1016/s1364-6613(99)01417-5

Galton, F. (1879a). Psychometric facts. *The Nineteenth Century: A Monthly Review, 5*(25), 425-433.

Galton F. (1879b). Psychometric experiments. *Brain*, 2, 149–162.

Gara, M. A., & Rosenberg, S. (1985). The multiplicity of personal identity. In P. Shaver (Ed.), *Self, situations, and social behavior: Review of personality and social psychology* (Vol. 6, pp. 217-238). Sage.

Gee, J. P. (1986). Units in the production of narrative discourse. *Discourse processes, 9,* 391-422

Ghosh, S., Tamuli, K. K., & Dihingia, S. (2007). A case presented with "as if" phenomenon. *Indian journal of psychiatry*, *49*(4), 292–293. https://doi.org/10.4103/0019-5545.37673

Giesbrecht, T., & Merckelbach, H. (2004). Subjective sleep experiences are related to dissociation. *Personality and Individual Differences, 37*, 1341–1345. https://doi.org/doi:10.1016/j.paid.2004.01.004

Artioli, G., Cosentino, C., Taffurelli, C., Ferri, P., & Foà, C. (2019). The narrative interview for the assessment of the assisted person: structure, method and data analysis. *Acta bio-medica: Atenei Parmensis, 90*(6-S), 7–16. https://doi.org/10.23750/abm.v90i6S.8640

Goffman, E. (1959). *The presentation of self in everyday life*. Doubleday.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall.

Golay, P., Alameda, L., Baumann, P., Elowe, J., Progin, P., Polari, A., & Conus, P. (2016). Duration of untreated psychosis: Impact of the definition of treatment onset on its predictive value over three years of treatment. *Journal of Psychiatric Research*, *77*, 15–21. https://doi.org/10.1016/j.jpsychires.2016.02.017

Gonĉcalves, O. F. (1994). Cognitive narrative psychotherapy: The hermeneutic construction of alternative meanings. *Journal of Cognitive Psychotherapy, 8*(2), 105–125.

Good, B. J., & Del Vecchio Good, M. J. (1994). In the subjunctive mode: epilepsy narratives in Turkey. *Social science & medicine, 38*(6), 835–842. https://doi.org/10.1016/0277-9536(94)90155-4

Gronholm, P., Thornicroft, G., Laurens, K., & Evans-Lacko, S. (2017). Mental health-related stigma and pathways to care for people at risk of psychotic disorders or experiencing first-episode psychosis: A systematic review. *Psychological Medicine, 47*(11), 1867–1879. https://doi.org/10.1017/S0033291717000344

Gubrium, J. F., & Holstein, J. A. (1998). Narrative practice and the coherence of personal stories. *Sociological quarterly*, *39*(1), 163-187.

Gwyther, M., Lenggenhager, B., Windt, J., Aspell, J. E., & Ciaunica, A. (2023). Living in a Bad Dream – Examining the Association between Depersonalisation Traits and the Bodily Self in Waking and Dreaming. *Scientific Reports, 14*(6107). https://doi.org/10.1038/s41598-024-56119-w

Haft, J. (2015). "I Hear My Voice, But Who Is Talking?": Understanding Depersonalization. *The Psychoanalytic quarterly*, *84*(4), 867–892. https://doi.org/10.1002/psaq.12041160940691989922O.

Hannes, K., Lockwood, C., & Pearson, A. (2010). A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research. *Qualitative health research, 20*(12), 1736–1743. https://doi.org/10.1177/1049732310378656

Hansard. (2019, March 12). Depersonalisation disorder: NHS treatment. [House of Commons Debate, Volume 656]. Depersonalisation Disorder: NHS Treatment - Hansard - UK Parliament

Hansson, L., Lexén, A., & Holmén, J. (2017). The effectiveness of narrative enhancement and cognitive therapy: a randomized controlled study of a self-stigma intervention. *Social Psychiatry & Epidemiology, 52*, 1415–1423. https://doi.org/10.1007/s00127-017-1385-x

Harper, D. (2011) 'Choosing a qualitative research method', in Harper, D., & Thompson, A. R. (eds.), *Qualitative research methods in mental health and psychotherapy*: Wiley-Blackwell, pp. 83-98.

Harter, S. (1998). The effects of child abuse on the self system. *Journal of Aggression, Maltreatment & Trauma*, *2*(1), 147–169. https://doi.org/10.1300/J146v02n01_09

Hartmann, E. (1995). Making connections in a safe place: Is dreaming psychotherapy?. *Dreaming*, *5*(4), 213–228. https://doi.org/10.1037/h0094437m.

Hawke, L. D., Anh T.P. Nguyen, Rodak, T., Yanos, P. T., & Castle, D. J. (2023). Narrative-based psychotherapies for mood disorders: A scoping review of the literature. *SSM - Mental Health*, *3*, 100224–100224. https://doi.org/10.1016/j.ssmmh.2023.100224

Heaton, K. J., Hill, C. E., Hess, S. A., Leotta, C., & Hoffman, M. A. (1998). Assimilation in therapy involving interpretation of recurrent and nonrecurrent dreams. *Psychotherapy: Theory, Research, Practice, Training, 35*(2), 147–162. https://doi.org/10.1037/h0087791

Hill, C. E., & Knox, S. (2010). The use of dreams in modern psychotherapy. *International Review of Neurobiology*, *92*, 291–317. https://doi.org/10.1016/s0074-7742(10)92013-8

Hirakata, P. (2009). Narratives of Dissociation: Insights into the Treatment of Dissociation in Individuals Who Were Sexually Abused as Children. *Journal of Trauma & Dissociation*, *10*(3), 297–314. https://doi.org/10.1080/15299730902956804

Holbæk, I., & Vrabel, K. (2024). "Now there are fewer of me": A qualitative study of the impact of psychoeducative groups for complex dissociative disorder. *European Journal of Trauma & Dissociation, 8*(2). https://doi.org/10.1016/j.ejtd.2024.100390

Hollan, D. (2004). The anthropology of dreaming: Selfscape dreams. *Dreaming*, *14*(2–3), 170–182. https://doi.org/10.1037/1053-0797.14.2-3.170

Hollan, D. W., & Wellenkamp, J. C. (1994). *Contentment and Suffering: Culture and Experience in Toraja* (illustrated ed.). Columbia University Press.

Hollan, D. W., & Wellenkamp, J. C. (1996). *The Thread of Life: Toraja Reflections on the Life Cycle*. University of Hawai'i Press. http://www.jstor.org/stable/j.ctt6wqx2m

Hollander, H. E. (2009). ECEM (Eye Closure, Eye Movements): Application to Depersonalization Disorder. *American Journal of Clinical Hypnosis*, *52*(2), 95–109. https://doi.org/10.1080/00029157.2009.10401701

Hollway, W., & Jefferson, T. (2000). *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method*. Sage Publications, London.

Hollway, W., & Jefferson, T. (2001). Free association, narrative analysis and the defended subject: The case of Ivy. *Narrative Inquiry*, *11*(1), 103–122. https://doi.org/10.1075/ni.11.1.07hol

Hollway, W., & Jefferson, T. (2008). *The free association narrative interview method. In L. M. Given* (Ed.), *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 296–315). Sevenoaks, California: Sage.

Hollway, W., & Jefferson, T. (2013). *Doing Qualitative Research Differently: A Psychosocial Approach. 2*. Sage Publications, London.

Hooks, B. (1989). *Talking back: Thinking Feminist, Thinking Black*. New York, NY: South End Press.

Horney, K. (1951). *Neurosis and human growth: the struggle towards self-realization*. London: Routledge & Kegan Paul Ltd.

Hunter, E. C. M., Sierra, M., & David, A. S. (2004a). The epidemiology of depersonalization and Serialization: a systematic review. *Social Psychiatry and Psychiatric Epidemiology*, 39(1), 9-18. https://doi.org/10.1007/s00127-004-0701-4

Hunter, E. C. M., Phillips, M. L., Chalder, T., Sierra, M., & David, A. S. (2004b). Depersonalisation disorder: A cognitive–behavioural conceptualisation. *Behaviour Research and Therapy*, *41*(12), 1451–1467. https://doi.org/10.1016/s0005-7967(03)00066-4

Hydén, L.C. (2008). Illness and narrative. *Sociology of Health & Illness*, *19*(1), 48–69. https://doi.org/10.1111/j.1467-9566.1997.tb00015.x

Hyland, P., Shevlin, M., & Brewin, C. R. (2023). The memory and identity theory of ICD-11 complex posttraumatic stress disorder. *Psychological review, 130*(4), 1044–1065. https://doi.org/10.1037/rev0000418

Ide, Y., & Beddoe, L. (2024). Challenging perspectives: Reflexivity as a critical approach to qualitative social work research. *Qualitative Social Work, 23*(4), 725-740. https://doi.org/10.1177/14733250231173522

Irvine A., Drew P., & Sainsbury R. (2013). 'Am I not answering your questions properly?' Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. *Qualitative Research, 13*(1), 87–106. https://doi.org/10.1177/1468794112439086

Jacobson, D., & Mustafa, N. (2019). Social Identity Map: A Reflexivity Tool for Practicing Explicit Positionality in Critical Qualitative Research. *International Journal of Qualitative Methods, 18*. https://doi.org/10.1177/1609406919870075

Jacobson, L., Fox, J., Bell, H., Zeligman, M., & Graham, J. (2015). Survivors with dissociative identity disorder: Perspectives on the counseling process. *Journal of Mental Health Counseling, 37*(4), 308–322. https://doi.org/10.17744/mehc.37.4.03

James, W. (1980). *The Principles of Psychology*. New York: Holt.

Janet, P. (1889). *L'automatisme psychologique*. Félix Alcan.

Jones, R. A. (2002). The Necessity of the Unconscious. *Journal for the Theory of Social Behaviour*, *32*(3), 344–365. https://doi.org/10.1111/1468-5914.00191

Joseph, F. I., Earland, J., & Ahmed, M. A. (2021). Experience of Conducting Sensitive Qualitative Research as a Cultural Outsider: Formulation of a Guide for Reflexivity.

International Journal of Qualitative Methods, 20. https://doi.org/10.1177/16094069211058616

Jović, V., Varvin, S., Rosenbaum, B., Fischmann, T., Opačić, G., Hau, S. (2018). Sleep Studies in Serbian Victims of Torture: Analysis of Traumatic Dreams. In: Vermetten, E., Germain, A., Neylan, T. (eds) *Sleep and Combat-Related Post Traumatic Stress Disorder*. Springer, New York, NY. https://doi.org/10.1007/978-1-4939-7148-0_34

Kearney, B. E., & Lanius, R. A. (2022). The brain-body disconnect: A somatic sensory basis for trauma-related disorders. *Frontiers in neuroscience*, *16*, 1015749. https://doi.org/10.3389/fnins.2022.1015749

Keen, S., Lomeli-Rodriguez, M., & Joffe, H. (2022). From Challenge to Opportunity: Virtual Qualitative Research During COVID-19 and Beyond. *International Journal of Qualitative Methods, 21*, https://doi.org/10.1177/16094069221105075

Kethawath, S. M., Krishna B, C., Pingali, S., & M, U. (2021). Depersonalization - derealization syndrome: A case report. *Telangana Journal of Psychiatry*, *6*(2), 185–186. https://doi.org/10.18231/j.tjp.2020.038

Kleindienst, N., Limberger, M. F., Ebner-Priemer, U. W., Keibel-Mauchnik, J., Dyer, A., Berger, M., Schmahl, C., & Bohus, M. (2011). Dissociation predicts poor response to Dialectial Behavioral Therapy in female patients with Borderline Personality Disorder. *Journal of personality disorders*, *25*(4), 432–447. https://doi.org/10.1521/pedi.2011.25.4.432

Kohut, H. (1977). *The restoration of the self*. Madison, CT: International Universities Press.

Krishaber, M. (1873). *De la névropathie cérébro-cardiaque [On cerebro-cardiac neuropathy]*. Paris, France: Georges et Cie.

Krishnan D. (2021). Orchestration of dreams: a possible tool for enhancement of mental productivity and efficiency. *Sleep and biological rhythms*, *19*(3), 207–213. https://doi.org/10.1007/s41105-021-00313-0

Labov, W. (Ed.). (1972). The transformation of experience in narrative syntax. In W. Labov (Ed.), *Language in the inner city: Studies in the black English vernacular* (pp. 354-396). Philadelphia: University of Pennsylvania Press.

Lambert, M. V., Sierra, M., Phillips, M. L., & David, A. S. (2002). The spectrum of organic depersonalization. *Journal of Neuropsychiatry and Clinical Neurosciences, 14*(2), 141-154. https://doi.org/10.1176/jnp.14.2.141

Langeland, W., Jepsen, E. K. K., Brand, B. L., Kleven, L., Loewenstein, R. J., Putnam, F. W., Schielke, H. J., Myrick, A., Lanius, R. A., & Heir, T. (2020). The economic burden of dissociative disorders: A qualitative systematic review of empirical studies. *Psychological Trauma: Theory, Research, Practice, and Policy*, *12*(7), 730–738. https://doi.org/10.1037/tra0000556

Lanius, R. A., Vermetten, E., Loewenstein, R. J., Brand, B., Schmahl, C., Bremner, J. D., & Spiegel, D. (2010). Emotion Modulation in PTSD: Clinical and Neurobiological Evidence for a Dissociative Subtype. *American Journal of Psychiatry*, *167*(6), 640–647. https://doi.org/10.1176/appi.ajp.2009.09081168

Lanius, U. F., Paulsen, S. L., & Corrigan, F. M. (2014). *Neurobiology and treatment of traumatic dissociation towards an embodied self*. Springer.

Lee, M. (2018). A Phenomenological Study of Reflective Awareness in Dreams: Characteristics of Attention, Memory, and Anticipation. *International Journal of Dream Research, 11*(1), 6–12. https://doi.org/10.11588/ijodr.2018.1.40338

Leonard, L., & Dawson, D. (2018). The marginalisation of dreams in clinical psychological practice. *Sleep Medicine Reviews*, *42*, 10–18. https://doi.org/10.1016/j.smrv.2018.04.002

Levin, R., & Fireman, G. (2002). Phenomenal qualities of nightmare experience in a prospective study of college students. *Dreaming*, *12*(2), 109–120. https://doi.org/10.1023/a:1015315707100

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the Critical Appraisal Skills Programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences, 1*(1), 31-42. https://doi.org/10.1177/2632084320947559

Loots, G., Coppens, K., & Sermijn, J. (2013). Practising a rhizomatic perspective in narrative research. In M. Andrews, C. Squire, M. Tamboukou (Eds.) *Practising a rhizomatic perspective in narrative research* (Second Edition ed., pp. 108-125). SAGE Publications, Ltd, https://doi.org/10.4135/9781526402271

Lucius-Hoene, G. (2000). Constructing and Reconstructing Narrative Identity. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *1*(2). https://doi.org/10.17169/fqs-1.2.1087

Lucius-Hoene, G., Holmberg, C., & Meyer, T. (Eds.). (2018). *Illness Narratives in Practice: Potentials and Challenges of Using Narratives in Health-related Contexts*. Oxford University Press. https://doi.org/10.1093/med/9780198806660.001.0001

Luney, L. T. (2022). Like our foremothers survived: Self-education, direct confrontation, and humor as resistance coping in Black womxn and femme college student being. *Frontiers in Education*, *7*. https://doi.org/10.3389/feduc.2022.932387

Lupien, S. J., Juster, R., Raymond, C., & Marin, M. (2018). The effects of chronic stress on the human brain: from neurotoxicity to vulnerability to opportunity. *Frontiers in Neuroendocrinology, 49*, 91-105. https://doi.org/10.1016/j.yfrne.2018.02.001

Lynn, S. J., Polizzi, C., Merckelbach, H., Chiu, C.-D., Maxwell, R., van Heugten, D., & Lilienfeld, S. O. (2022). Dissociation and dissociative disorders reconsidered: Beyond sociocognitive and trauma models toward a transtheoretical framework. *Annual Review of Clinical Psychology*, *18*(1), 259–289. https://doi.org/10.1146/annurev-clinpsy-081219-102424

Lyssenko, L., Schmahl, C., Bockhacker, L., Vonderlin, R., Bohus, M., & Kleindienst, N. (2018). Dissociation in psychiatric disorders: A meta-analysis of studies using the Dissociative Experiences Scale. *American Journal of Psychiatry, 175*(1), 37-46. https://doi.org/10.1176/appi.ajp.2017.17010025

Macduffie, K., & Mashour, G. (2010). Dreams and the temporality of Consciousness. The *American Journal of Psychology, 123(2),* 189–197. https://doi.org/10.5406/amerjpsyc.123.2.0189

Madigan, S. (2011). *Narrative therapy*. American Psychological Association.

Malinowski, J. E., & Horton, C. L. (2015). Metaphor and hyperassociativity: the imagination mechanisms behind emotion assimilation in sleep and dreaming. *Frontiers in psychology*, *6*, 1132. https://doi.org/10.3389/fpsyg.2015.01132

Mantzoukas, S. (2005). The inclusion of bias in reflective and reflexive research: A necessary prerequisite for securing validity. *Journal of Research in Nursing*, *10*(3), 279-295. https://doi.org/10.1177/174498710501000305

Marks, S., & Monnich-Marks, H. (2003) The analysis of counter-transference reactions is a means to discern latent interview-contents. *Forum: Qualitative Social Research,* 4(2). https://doi.org/10.17169/fqs-4.2.709

Markus, H. R., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review*, *98*(2), 224–253. https://doi.org/10.1037/0033-295X.98.2.224

Markus, H., & Wurf, E. (1987). The dynamic self-concept: A social psychological perspective. In M. R. Rosenzweig & L. W. Porter (Eds.), *Annual review of psychology,* (Vol. 38, pp. 299–337). Annual Reviews.

Marogna, C., Montanari, E., Contiero, S., & Lleshi, K. (2021). Dreaming during COVID-19: The effects of a world trauma. *Research in Psychotherapy: Psychopathology, Process and Outcome, 24*(2), 541. https://doi.org/10.4081/ripppo.2021.541

Mauritz, M. W., van Gaal, B. G., Goossens, P. J., Jongedijk, R. A., & Vermeulen, H. (2021). Treating patients with severe mental illness with narrative exposure therapy for comorbid post-traumatic stress disorder. *BJPsych Open*, *7*(1), e12.

Mauritz, M., Goossens, P., Jongedijk, R., Vermeulen, H., & Van Gaal, B. (2022). Investigating the Efficacy and Experiences With Narrative Exposure Therapy in Severe Mentally Ill Patients With Comorbid Post-traumatic Stress Disorder Receiving Flexible Assertive Community Treatment: A Mixed Methods Study. *Frontiers in Psychiatry*, *13*. https://doi.org/10.3389/fpsyt.2022.804491

Mayer-Gross, W. (1935). On depersonalization. *British Journal of Medical Psychology, 15,* 103-122. https://doi.org/10.1111/j.2044-8341.1935.tb01140.x

McAdams, D. P., & McLean, K. C. (2013). Narrative identity. *Current Directions in Psychological Science,22*(3), 233–238. 10.1177/0963721413475622

McAdams, D. P. (2018). Narrative Identity: What Is It? What Does It Do? How Do You Measure It?. *Imagination, Cognition and Personality, 37*(3), 359–372. https://doi.org/10.1177/0276236618756704.

McAllum, K., Fox, S., Simpson, M., & Unson, C. (2019). A comparative tale of two methods: how thematic and narrative analyses author the data story differently. *Communication Research and Practice, 5*(4), 358–375. https://doi.org/10.1080/22041451.2019.1677068

McGillicuddy, T. P. (2013). *Sacred dreams & life-limiting illness: A depth psychospiritual approach*. WestBow Press.

McLean, K. C., & Syed, M. (2015). Personal, Master, and Alternative Narratives: An Integrative Framework for Understanding Identity Development in Context. *Human Development*, *58*(6), 318–349. https://doi.org/10.1159/000445817

McLean, K. C., & Syed, M. (2015). Personal, Master, and Alternative Narratives: An Integrative Framework for Understanding Identity Development in Context. *Human Development*, *58*(6), 318–349. https://doi.org/10.1159/000445817

Medford, N., Sierra, M., Baker, D., & David, A. S. (2005). Understanding and treating depersonalisation disorder. *Advances in Psychiatric Treatment*, *11*(2), 92-100. https://doi.org/doi:10.1192/apt.11.2.92

Medford, N. (2012). Emotion and the Unreal Self: Depersonalization Disorder and De-Affectualization. Emotion Review, 4(2), 139-144. https://doi.org/10.1177/1754073911430135

Michaels, S. (1982). “Sharing time”: Children’s narrative styles and differential access to literacy. *Language and Society, 10,* 423-422. https://doi.org/10.1017/S0047404500008861

Michal, M., Wiltink, J., Tibubos, A. N., Wild, P. S., Münzel, T., Lackner, K., Pfeiffer, N., König, J., Gieswinkel, A., Beutel, M., & Kerahrodi, J. G. (2024). Impact of depersonalization on the course of depression: Longitudinal observations from the

Gutenberg Health Study. *BMC Psychiatry*, *24*(1). https://doi.org/10.1186/s12888-024-05658-7

Miller, D., Rees, J., & Pearson, A. (2021). "Masking is life": Experiences of masking in autistic and nonautistic adults. *Autism in Adulthood, 3*(4), 330–338. https://doi.org/10.1089/aut.2020.0083c

Mishler, E. G. (1999). *Storylines: Craft artists' narratives of identity*. Harvard University Press.

Mirjat, M. H., Kamran, M., Ashraf, H., Akhtar, H., & Lalwani, A. K. (2024). A Case Report of Primary Derealization Disorder: Diagnostic and Treatment Challenges in a Pakistani Healthcare Setting. *Cureus*, *16*(3), e55419. https://doi.org/10.7759/cureus.55419

Mizobe, Y., Yamada, K., & Fujii, I. (1992). The sequence of panic symptoms. *Japanese Journal of Psychiatry and Neurology, 46*(3), 597–601. https://doi.org/10.1111/j.1440-1819.1992.tb00533.x

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine*, *6*(7). https://doi.org/10.1371/journal.pmed.1000097

Moiseeva, N. I. (1975). The characteristics of EEG activity and the subjective estimation of time during dreams of different structure. *Electroencephalography and Clinical Neurophysiology, 38*(6), 569–577. https://doi.org/10.1016/0013-4694(75)90157-1

Molina, J. M. (1996). *Dissociation in dreams: The impact of dissociative tendency on dream content* (pp. 4076–4080) [PhD Thesis]. https://www.proquest.com/docview/304303188?pq-origsite=gscholar&fromopenview=true

Moon, K., & Blackman, D. (2014). A guide to understanding social science research for natural scientists. *Conservation Biology, 28*(5), 1167–1177. https://doi.org/10.1111/cobi.12326

Mula, M., Pini, S., Calugi, S., Preve, M., Masini, M., Giovannini, I., Conversano, C., Rucci, P., & Cassano, G. B. (2008). Validity and reliability of the Structured Clinical Interview for Depersonalization-Derealization Spectrum (SCI-DER). *Neuropsychiatric Disorder Treatment, 4*(5), 977-86.

NHS. (2021). Dissociative disorders. NHS. https://www.nhs.uk/mental-health/conditions/dissociative-disorders/

NHS. (2023, August 14). *Dissociative disorders*. National Health Service. https://www.nhs.uk/mental-health/conditions/dissociative-disorders/

National Institute for Health and Care Excellence (NICE). (2018). *Post-traumatic stress disorder. The management of PTSD in adults and children in primary and secondary care* [NICE Guideline No. 26]. https://www.nice.org.uk/guidance/ng116/evidence/march-2005-full-guideline-pdf-6602623598

Nester, M. S., Hawkins, S. L., & Brand, B. L. (2022). Barriers to accessing and continuing mental health treatment among individuals with dissociative symptoms. *European journal of psychotraumatology*, *13*(1), 2031594. https://doi.org/10.1080/20008198.2022.2031594

Nielsen, S. R., & Wright, A. G. C. (2025). The Structure of Identity Dysfunction in Self-Report Measures. *Journal of personality assessment*, *107*(1), 12–27. https://doi.org/10.1080/00223891.2024.2362982

Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., Pantoja, T., Hannes, K., Cargo, M., & Thomas, J. (2018). Cochrane qualitative and implementation

methods group guidance series – paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology, 97,* 49–58. https://doi.org/10.1016/j.jclinepi.2017.06.020

O'Connor, C., & Joffe, H. (2020). Intercoder reliability in qualitative research: debates and

Opsvik, Y. Ø., Holbæk, I., Arefjord, K., & Hjeltnes, A. (2022). The challenge of being present with yourself: Exploring the lived experience of individuals with complex dissociative disorders. *European Journal of Trauma & Dissociation, 6*(2). https://doi.org/10.1016/j.ejtd.2021.100250

Paget, M. A. (1983). Experience and Knowledge. *Human studies, 6,* 67-90. https://www.jstor.org/stable/20008864

Paley, K. S. (1992). Dream wars: A case study of a woman with multiple personality disorder. *Dissociation, 5*(2), 111–116.

Patihis, L., & Lynn, S. J. (2017). Psychometric comparison of Dissociative Experiences Scales II and C: A weak trauma-dissociation link. *Applied Cognitive Psychology, 31*(4), 392–403. https://doi.org/10.1002/acp.3337

Pesant, N., & Zadra, A. (2004). Working with dreams in therapy: what do we know and what should we do?. *Clinical psychology review*, *24*(5), 489–512. https://doi.org/10.1016/j.cpr.2004.05.002

Pesant, N., & Zadra, A. (2005). Dream content and psychological well-being: A longitudinal study of the continuity hypothesis. *Journal of Clinical Psychology*, *62*(1), 111–121. https://doi.org/10.1002/jclp.20212

Phillips, M., & Frederick, C. (1995). *Healing the divided self: Clinical and Ericksonian hypnotherapy for post-traumatic and dissociative conditions*. New York, NY: W.W. Norton & Co.

Pienkos, E. & Sass, L. (2022). "Robbed of my life": The Felt Loss of Familiar and Engaged Presence in Depersonalization/Derealization Disorder. *Journal of Phenomenological Psychology*, *53*(1), 51-81. https://doi.org/10.1163/15691624-20221398

Pietkiewicz, I. J., Banbura-Nowak, A., Tomalski, R., & Boon, S. (2021). Revisiting false-positive and imitated dissociative identity disorder. *Frontiers in Psychology, 21*, 637929. https://doi.org/10.3389/fpsyg.2021.

Polizzi, C. P., Aksen, D. E., & Lynn, S. J. (2022). Quality of life, emotion regulation, and dissociation: Evaluating unique relations in an undergraduate sample and probable PTSD subsample. *Psychological Trauma: Theory, Research, Practice, and Policy, 14*(1), 107–115. https://doi.org/10.1037/tra0000904

Powers, A., Cross, D., Fani, N., & Bradley, B. (2015). PTSD, emotion dysregulation, and dissociative symptoms in a highly traumatized sample. *Journal of Psychiatric Research, 61*, 174-179. https://doi.org/10.1016/j.jpsychires.2014.12.011

Prince, M. (1910). The mechanism and interpretation of dreams. *Journal of Abnormal Psychology, 5,* 139-195. https://doi.org/10.1037/h0070883

Qin, P., Wang, M., & Northoff, G. (2020). Linking bodily, environmental and mental states in the self-A three-level model based on a meta-analysis. *Neuroscience and biobehavioral reviews, 115*, 77–95. https://doi.org/10.1016/j.neubiorev.2020.05.004

Rahim, H. F., Mooren, T. T. M., Van Den Brink, F., Knipscheer, J. W., & Boelen, P. A. (2021). Cultural Identity Conflict and Psychological Well-Being in Bicultural Young Adults: Do Self-Concept Clarity and Self-Esteem Matter?. *The Journal of nervous and mental disease, 209*(7), 525–532. https://doi.org/10.1097/NMD.0000000000001332

Ramanathan, V. (1997). *Alzheimer Discourse*. Routledge.

Rassin, E., Merckelbach, H., & Spaan, V. (2001). When Dreams Become a Royal Road to Confusion: Realistic Dreams, Dissociation, and Fantasy Proneness. *The Journal of Nervous and Mental Disease*, *189*(7), 478–481. https://doi.org/10.1097/00005053-200107000-00010

Ratcliffe, M., & Byrne, E. A. (2022). Grief, self and narrative. *Philosophical Explorations*, *25*(3), 319–337. https://doi.org/10.1080/13869795.2022.2070241

Reik, T. (1948). *Listening with the third ear; the inner experience of a psychoanalyst*. Farrar, Straus & Co.

Renard, S. B., Huntjens, R. J. C., Lysaker, P. H., Moskowitz, A., Aleman, A., & Pijnenborg, G. H. M. (2017). Unique and Overlapping Symptoms in Schizophrenia Spectrum and Dissociative Disorders in Relation to Models of Psychopathology: A Systematic Review. *Schizophrenia Bulletin*, *43*(1), 108–121. https://doi.org/10.1093/schbul/sbw063

Riessman, C. K. (1993). *Narrative analysis*. Sage Publications, Inc.

Ritchie, J., Lewis, J., McNaughton Nicholls, C., & Ormston, R. (2013). *Qualitative research practice: a guide for social science students and researchers*. SAGE.

Roberts, J. K., Pavlakis, A. E., & Richards, M. P. (2021). It's more complicated than it seems: Virtual qualitative research in the COVID-19 era. *International Journal of Qualitative Methods, 20,* 1–13. https://doi.org/10.1177/16094069211002959

Robinson, J. A. and Hawpe, L. (1986). Heuristic uses of narrative thinking. In T. R. Sarbin (ed.), *Narrative psychology* (pp. 111–125). New York: Praeger.

Roesler, C. (2018). Dream content corresponds with dreamer's psychological problems and personality structure and with improvement in psychotherapy: A typology of dream patterns in dream series of patients in analytical psychotherapy. *Dreaming, 28*(4), 303–321.

Rosenthal, G. (1990). The Structure and 'Gestalt' of Autobiographies and its Methodological Consequences [unpublished paper presented at twelfth World Congress of Sociology conference]. The World Congress of Sociology, Madrid.

Rosenthal, G. (1993). Reconstruction of life stories: Principles of selection in generating stories for narrative biographical interviews. In R. Josselson & A. Lieblich (Eds.), *The narrative study of lives*, Vol. 1, pp. 59–91). Sage Publications, Inc

Roth, M. (1959). The phobic anxiety-depresonalization syndrome. *Proceedings of the Royal Society of Medicine*, *52*(8), 587–595.

Roth, M., & Argyle, N. (1988). Anxiety, panic and phobic disorders: An overview. *Journal of Psychiatric Research*, *22*, 33–54. https://doi.org/10.1016/0022-3956(88)90068-4

Rüfenacht, E., Shaverin, L., Stubley, J., Smits, M. L., Bateman, A., Fonagy, P., & Luyten, P. (2023). Addressing dissociation symptoms with trauma-focused mentalization-based treatment. *Psychoanalytic Psychotherapy*, *37*(4), 1–25. https://doi.org/10.1080/02668734.2023.2272765

Rufer, M., Held, D., Cremer, J., Fricke, S., Moritz, S., Peter, H., & Hand, I. (2006). Dissociation as a predictor of cognitive behavior therapy outcome in patients with obsessive-compulsive disorder. *Psychotherapy and Psychosomatics, 75*(1), 40–46. https://doi.org/10.1159/000089225

Rüsch, N., Corrigan, P. W., Wassel, A., Michaels, P., Olschewski, M., Wilkniss, S., & Batia, K. (2009). Ingroup perception and responses to stigma among persons with mental illness. *Acta Psychiatrica Scandinavica*, *120*, 320–328. https://doi.org/10.1111/j.1600-0447.2009.01403.x

Sackwild, L., & Stumbrys, T. (2021). The healing and transformative potential of lucid dreaming for treating clinical depression. *International Journal of Dream Research*, *14*(2), 296–308. https://doi.org/10.11588/ijodr.2021.2.81533

Sadger, I. (1928) Über Depersonalisation. *Internationale Zeitschrift für Psychoanalyse, 14*(3), 315-351.

Scalabrini, A., Esposito, R., & Mucci, C. (2021). Dreaming the unrepressed unconscious and beyond: repression *vs* dissociation in the oneiric functioning of severe patients. *Research in psychotherapy (Milano)*, *24*(2), 545. https://doi.org/10.4081/ripppo.2021.545

Scheffelaar, A., Janssen, M., & Luijkx, K. (2021). The Story as a Quality Instrument: Developing an Instrument for Quality Improvement Based on Narratives of Older Adults Receiving Long-Term Care. *International Journal of Environmental Research and Public Health*, *18*(5), 2773. https://doi.org/10.3390/ijerph18052773

Schilder, P. (1939). The treatment of depersonalization. *Bulletin of the New York academy of medicine, 15*(4), 258-272.

Schredl, M. (2006). Factors Affecting the Continuity Between Waking and Dreaming: Emotional Intensity and Emotional Tone of the Waking-Life Event. *Sleep and Hypnosis*, *8*(1), 1-5.

Schredl, M., & Hofmann, F. (2003). Continuity between waking activities and dream activities. *Consciousness and Cognition*, *12*(2), 298–308. https://doi.org/10.1016/s1053-8100(02)00072-7

Schröder, J., Kratzer, L., Yamak, Y., Briken, P., & Tozdan, S. (2021). The role of stigmatization in developing post-traumatic symptoms after experiencing child sexual abuse by a female perpetrator. *European Journal of Psychotraumatology, 12*(1). https://doi.org/10.1080/20008198.2021.1966982

Schütze, F. (1976). Zur Hervorlockung und Analyse von Erzählungen thematisch relevanter Geschichten im Rahmen soziologischer Feldforschung - Dargestellt an einem Projekt

zur Erforschung von kommunalen Machtstrukturen. In Arbeitsgruppe Bielefelder Soziologen (ed) *Kommunikative Sozialforschung*. München: Fink, pp. 159–260.

Schütze, F. (1992a). Pressure And Guilt: War Experiences Of A Young German Soldier And Their Biographical Implications (Part 1). *International Sociology*, *7*(2), 187–208. https://doi.org/10.1177/026858092007002005

Schütze, F. (1992b). Pressure And Guilt: War Experiences Of A Young German Soldier And Their Biographical Implications (Part 2). *International Sociology*, *7*(3), 347–367. https://doi.org/10.1177/026858092007003006

Seedat, S., Stein, M. B., & Forde, D. R. (2003). Prevalence of dissociative experiences in a community sample: Relationship to gender, ethnicity, and substance use. *The Journal of Nervous and Mental Disease, 191*(2), 115-120. https://doi.org/10.1097/01.NMD.0000050940.16782.6B

Shankley, W., Stalford, H., Chase, E., Iusmen, I., & Kreppner, J. (2023). What does it mean to adopt a trauma-informed approach to research?: Reflections on a Participatory project with young people seeking asylum in the UK. *International Journal of Qualitative Methods*, *22*. https://doi.org/10.1177/16094069231183605

Shapiro, J. (2011). Illness narratives: Reliability, authenticity and the empathic witness. *Medical Humanities, 37*(2), 68–72. https://doi.org/10.1136/jmh.2011.007328

Sierra, M., Gomez, J., Molina, J. J., Luque, R., Muñoz, J. F., & David, A. S. (2006). Depersonalization in psychiatric patients: a transcultural study. *Journal of Nervous and Mental Disease, 194*(5), 356-61. https://doi.org/10.1097/01.nmd.0000218071.32072.74.

Sierra, M. (2008). Depersonalization disorder: pharmacological approaches. *Expert Review of Neurotherapeutics*, *8*(1), 19–26. https://doi.org/10.1586/14737175.8.1.19

Sierra, M. (2009). *Depersonalization: A New Look at a Neglected Syndrome*. New York, NY: Cambridge University Press.

Sierra, M., & Berrios, G. E. (1997). Depersonalization: A conceptual history. *History of Psychiatry*, *8*(30), 213–229. https://doi.org/10.1177/0957154x9700803002

Sierra, M., & Berrios, G. E. (2000). The Cambridge Depersonalisation Scale: a new instrument for the measurement of depersonalisation. *Psychiatry Research*, *93*(2), 153–164. https://doi.org/10.1016/s0165-1781(00)00100-1

Sikka, P., Pesonen, H., & Revonsuo, A. (2018). Peace of mind and anxiety in the waking state are related to the affective content of dreams. *Scientific reports*, *8*(1). https://doi.org/10.1038/s41598-018-30721-1

Simeon, D., Gross, S., Guralnik, O., Stein, D. J., Schmeidler, J., & Hollander, E. (1997). Feeling unreal: 30 cases of DSM-III-R depersonalization disorder. *The American journal of psychiatry, 154*(8), 1107–1113. https://doi.org/10.1176/ajp.154.8.1107

Sirvent, C., & Fernández, L. (2015). Depersonalization Disorder in Former Addicts (Prevalence of Depersonalization-Derealization Disorder in Former Addicts). *Journal of Addiction Research & Therapy*, *06*(2). https://doi.org/10.4172/2155-6105.1000225

Smits, M. L., De Vos, J., Rüfenacht, E., Nijssens, L., Shaverin, L., Nolte, T., Luyten, P., Fonagy, P., & Bateman, A. (2024). Breaking the cycle with trauma-focused mentalization-based treatment: theory and practice of a trauma-focused group intervention. *Frontiers in psychology*, *15*. https://doi.org/10.3389/fpsyg.2024.1426092

Soffer-Dudek, N. (2017). Daily Elevations in Dissociative Absorption and Depersonalization in a Nonclinical Sample Are Related to Daily Stress and Psychopathological Symptoms. *Psychiatry, 80*(3), 265-278. https://doi.org/10.1080/00332747.2016.1247622.

Solomonova, E., Picard-Deland, C., Rapoport, I. L., Pennestri, M.-H., Saad, M., Kendzerska, T., Veissiere, S. P. L., Godbout, R., Edwards, J. D., Quilty, L., & Robillard, R. (2021). Stuck in a lockdown: Dreams, bad dreams, nightmares, and their relationship to stress, depression and anxiety during the COVID-19 pandemic. *PLOS ONE*, *16*(11). https://doi.org/10.1371/journal.pone.0259040

Spangler, P. T., & Sim, W. (2023). Dream work and nightmare treatments. In C. E. Hill & J. C. Norcross (Eds.), *Psychotherapy skills and methods that work* (pp. 577–604). Oxford University Press. https://doi.org/10.1093/oso/9780197611012.003.0019

Spector-Mersel, G. (2010). Narrative research: Time for a paradigm. *Narrative Inquiry*, *20*(1), 204–224. https://doi.org/10.1075/ni.20.1.10spe

Spiegel, D., Loewenstein, R. J., Lewis-Fernández, R., Sar, V., Simeon, D., Vermetten, E., Cardeña, E., & Dell, P. F. (2011). Dissociative disorders in DSM-5. *Depression and Anxiety, 28*(9), 824-852. https://doi.org/10.1002/da.20874

Squire, C., Andrews, M., & Tamboukou, M. (2013). Introduction: what is narrative research?. In M. Andrews, C. Squire, M. Tamboukou (Eds.) *Doing narrative research* (pp. 1-21). SAGE Publications, Ltd., https://doi.org/10.4135/9780857024992

Steinberg, M. (1994). *Structured Clinical Interview for DSM-IV Dissociative Disorders-Revised (SCID-D-R)*. Washington, DC: American Psychiatric Press.

Steinberg, M. (2023). *The SCID-D Interview: Dissociation Assessment in Therapy, Forensics, and Research*. American Psychiatric Association Publishing.

Stolorow, R. D., & Atwood, G. E. (1989). The unconscious and unconscious fantasy: An intersubjective-developmental perspective. *Psychoanalytic Inquiry, 9*(3), 364-374. https://doi.org/10.1080/07351698909533773

Terock, J., Van der Auwera, S., Janowitz, D., Spitzer, C., Barnow, S., Miertsch, M., Freyberger, H. J., & Grabe, H. J. (2016). From childhood trauma to adult dissociation: The role of PTSD and alexithymia. *Psychopathology*, *49*(5), 374-382. https://doi.org/10.1159/000449004

Thoits, P. A. (2013). Self, identity, stress, and mental health. In C. S. Aneshensel, J. C. Phelan., & A. Bierman (Eds.), *Handbook of the sociology of mental health* (2nd ed., pp. 357–377). Springer Science & Business Media. https://doi.org/10.1007/978-94-007-4276-5_18

Thomas, C., Reeve, J., Bingley, A., Brown, J., Payne, S., & Lynch, T. (2009). Narrative research methods in palliative care contexts: two case studies. *Journal of pain and symptom management*, *37*(5), 788-796.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(45). https://doi.org/10.1186/1471-2288-8-45

Titus, B., & De Souza, R. (2011). Finding Meaning in the Loss of a Child: Journeys of Chaos and Quest. *Health Communication*, *26*(5), 450–460. https://doi.org/10.1080/10410236.2011.554167

Torch, E. M. (1978). Review of the relationship between obsession and depersonalization. *Acta Psychiatrica Scandinavica*, *58*(2), 191-198. https://doi.org/10.1111/j.1600-0447.1978.tb06931.x

Van Der Kloet, D., Merckelbach, H., Giesbrecht, T., & Lynn, S. J. (2012a). Fragmented Sleep, Fragmented Mind. *Perspectives on Psychological Science*, *7*(2), 159–175. https://doi.org/10.1177/1745691612437597

Van Der Kloet, D., Giesbrecht, T., Lynn, S. J., Merckelbach, H., & De Zutter, A. (2012b). Sleep normalization and decrease in dissociative experiences: Evaluation in an

inpatient sample. *Journal of Abnormal Psychology*, *121*(1), 140–150. https://doi.org/10.1037/a0024781

Van Der Kolk, B. A., & Van Der Hart, O. (1989). Pierre Janet and the breakdown of adaptation in psychological trauma. *American Journal of Psychiatry, 146*(12), 1530-40. https://doi.org/10.1176/ajp.146.12.1530

Van Heugten-Van Der Kloet, D., & Lynn, S. J. (2020). Dreams and Dissociation—Commonalities as a Basis for Future Research and Clinical Innovations. *Frontiers in Psychology*, *11*. https://doi.org/10.3389/fpsyg.2020.00745

Vanden Poel, L., & Hermans, D. (2019). Narrative Coherence and Identity: Associations With Psychological Well-Being and Internalizing Symptoms. *Frontiers in Psychology*, *10*. https://doi.org/10.3389/fpsyg.2019.01171

Victoria Derbyshire (2017, September, 26). The disorder that makes people unable to feel love [Video file]. Retrieved from https://www.bbc.co.uk/programmes/p05h8drf.

Wagner-Skacel, J., Riedl, D., Kampling, H., & Lampe, A. (2022). Mentalization and dissociation after adverse childhood experiences. *Scientific Reports, 12*. https://doi.org/10.1038/s41598-022-10787-8

Wang, S., Zheng, S., Zhang, F. X., Ma, R., Feng, S., Song, M., Zhu, H., & Jia, H. (2024). The treatment of depersonalization-derealization disorder: A systematic review. *Journal of Trauma & Dissociation, 25*(1), 6–29. https://doi.org/10.1080/15299732.2023.2231920

Waters, T. E., & Fivush, R. (2015). Relations Between Narrative Coherence, Identity, and Psychological Well-Being in Emerging Adulthood. *Journal of personality*, *83*(4), 441–451. https://doi.org/10.1111/jopy.12120

Watson, D. (2001). Dissociations of the night: Individual differences in sleep-related experiences and their relation to dissociation and schizotypy. *Journal of Abnormal Psychology*, *110*(4), 526–535. https://doi.org/10.1037/0021-843x.110.4.526

Watson, O. (2022). Embodying the (dis)embodiment: Narrating depersonalization-derealization disorder. *Qualitative Health Research*, *32*(12), 1858–1864. https://doi.org/10.1177/10497323221123763

Weiss, H. L., & Low, K. G. (2017). Dissociation and attention in relation to sleep and mood. *Psychology of Consciousness: Theory, Research, and Practice, 4*(4), 381–395. https://doi.org/10.1037/cns0000140

Wertheimer, M. (1938). Gestalt theory. In W. D. Ellis (Ed.), *A source book of Gestalt psychology* (pp. 1–11). Kegan Paul, Trench, Trubner & Company. https://doi.org/10.1037/11496-001

White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: Norton.

Williams, K. (2022). *"If I'm not me, who am I?": An art-based self-study examining the lived experience of an individual with diagnosed depersonalization disorder* (Master's thesis, Pratt Institute). Pratt Institute School of Art.

Winnicott, D. W. (1945). Primitive emotional development. *The International Journal of Psychoanalysis, 26,* 137–143.

Winnicott, Donald (1960). "Ego distortion in terms of true and false self". *The Maturational Process and the Facilitating Environment: Studies in the Theory of Emotional Development*. New York City: International Universities Press.

Wong, G., & Breheny, M. (2018). Narrative analysis in health psychology: a guide for analysis. *Health Psychology and Behavioral Medicine*, *6*(1), 245–261. https://doi.org/10.1080/21642850.2018.1515017

World Health Organization [WHO]. (2018). *International classification of diseases for mortality and morbidity statistics (11th Revision)*. Geneva: World Health Organization.

Yang, J., Millman, L. S. M., David, A. S., & Hunter, E. C. M. (2022). The Prevalence of Depersonalization-Derealization Disorder: A Systematic Review. *Journal of Trauma & Dissociation*, *24*(1), 1–34. https://doi.org/10.1080/15299732.2022.2079796

Yanos, P. T., Roe, D., & Lysaker, P. H. (2011). Narrative enhancement and cognitive therapy: a new group-based treatment for internalized stigma among persons with severe mental illness. *International journal of group psychotherapy*, *61*(4), 577–595. https://doi.org/10.1521/ijgp.2011.61.4.576

Young Minds. (2018). *Understanding trauma and adversity*. https://www.youngminds.org.uk/professional/resources/understanding-trauma-and-adversity/

Yu, C. K.-C. (2010). Dream intensity scale: Factors in the phenomenological analysis of dreams. *Dreaming, 20*(2), 107–129. https://doi.org/10.1037/a0019240

Zhang, J., Pena, A., Delano, N., Sattari, N., Shuster, A. E., Baker, F. C., Simon, K., & Mednick, S. C. (2024). Evidence of an active role of dreaming in emotional memory processing shows that we dream to forget. *Scientific reports, 14*(1). https://doi.org/10.1038/s41598-024-58170-z

Appendices

Appendix A

Dream Diary Study materials: morning and evening surveys, dream log prompts

Morning Survey

Good morning!

Dream log

- ○ I have one or more dreams to report today (1)
- ○ I have no dreaming to report today (2)

Your dream log

Please note down here your dream contents from last night. Anything you remember will be valuable, from vague feelings / notes to detailed accounts. An average dream log is around 150 words (twice as long as these instructions), but you can write more or less. Please number each distinct dream and avoid personally identifying information about yourself or others (full names or addresses). Please add context (e.g. relationship to dream person in real life) to help us understand how your dream relates to your waking life, but avoid interpreting the dream.

_____

_____

_____

_____

About your dream log

- ○ This is all I recall in as much detail as I remember (1)
- ○ I have left out some details or specific contents for my own reasons (2)

For the most emotional of any dreams last night, what was the main emotion felt in the dream (in one word or phrase)?

_____

How intensely was this emotion felt?
Dial from 0 for barely there to 10 for extremely intense

0 (0) 1 (1) 2 (2) 3 (3) 4 (4) 5 (5) 6 (6) 7 (7) 8 (8) 9 (9) 10 (10)

How would you categorise your dream(s)? Tick all that apply

- ☐ A lucid dream (dream in which you became aware that you were dreaming) (1)
- ☐ A nightmare (dream so disturbing, frightening or otherwise emotionally intense that it woke you from sleep) (2)
- ☐ A bad dream (negative dream that did not wake you from sleep) (3)
- ☐ A flying dream, unaided (dream in which you were flying or soaring through the air unaided) (4)
- ☐ A flying dream, aided (dream in which you were flying or soaring through the air aided by mechanical means of any kind) (5)
- ☐ Anything else (6)
- ☐

Please move the slider left or right to indicate your dream feelings

In my dream(s) I felt...

	very disconnected from my world	very immersed in my world
()		

In my dream(s) I felt...

	very disconnected from my bodily sensations and emotions	very connected with my bodily sensations and emotions

()

In my dream(s) I felt...

not at all like an actor / agent within the plot

very much like an actor / agent within the plot

()

In my dream(s) I felt...

not at all like an observer of the plot

very much like an observer of the plot

()

In my dream(s) I felt...

not at all “in my head” (thinking / reflecting)

very much “in my head” (thinking / reflecting)

()

My dream self felt...

much worse than I usually feel

much better than I usually feel

()

My dream(s) felt...

very incoherent / fragmented

very coherent

()

My dream(s) felt...

very unlikely to ever occur in my real life

very likely to occur in my real life

()

My dream(s) felt...

very unconnected to previous day's events

very connected to previous day's events

()

My dream(s) felt...

very unpleasant

very pleasant

()	

If you have DPDR, please also indicate how much you disagree or agree with these statements

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
In my dream(s) I felt more connected with my 'old', former self that I had before I developed DPDR (4)	○	○	○	○	○
In my dream(s) I experienced my self as disconnected in a similar way to my current waking DPDR self (5)	○	○	○	○	○

Please tell us about your sleep last night

Approximate time you went to bed in the evening

_____

Approximate time you got up in the morning

_____

Non-sleep periods?

	0-15 min (4)	16-30 min (3)	31-45 min (2)	46-60 min (1)	more than 60 min (0)
How long did it take you to fall asleep? (1)	○	○	○	○	○
If you then woke up during the night, how long were you awake in total? (add up all the waking periods) (2)	○	○	○	○	○

How would you rate your sleep **quantity** (how much you slept)?

- ○ Very poor (0)
- ○ Poor (1)
- ○ Average (2)
- ○ Good (3)
- ○ Very good (4)

How would you rate your sleep **quality** (how well you slept)?

- ○ Very poor (0)
- ○ Poor (1)
- ○ Average (2)
- ○ Good (3)
- ○ Very good (4)

If you have any other observations on your sleep or dreaming that you think may be useful for us to know, please note them here

_____

_____

_____

Finally, what date does your log refer to? If you are recording a dream log from a day that is NOT today, tick 'Another day' and enter the date your log refers to (e.g. enter '29th May' for a dream log for the night from 28th to 29th May)

- ○ Today (1)
- ○ Another day (please enter date) (2)

_____

Evening Survey

Good evening!

Please move the slider left or right to indicate your feelings during the day

Today I felt...

	very much like “in a dream”	very much “fully present” and “real”
()		

Today I felt...

	very disconnected from the world	very immersed in the world
()		

Today I felt...

	very disconnected from my bodily sensations and emotions	very connected with my bodily sensations and emotions
()		

Today I felt...

	not at all like an actor / agent within the day's events	very much like an actor / agent within the day's events
()		

Today I felt...

	not at all like an observer of the day's events	very much like an observer of the day's events
()		

Today I felt...

	not at all “in my head” (thinking / reflecting)	very much “in my head” (thinking / reflecting)

	()	
Today I felt...		
	much worse than I usually feel	much better than I usually feel
	()	
My reality felt...		
	very incoherent / fragmented	very coherent
	()	
My day felt...		
	very unpleasant	very pleasant

Please select what best describes your mental wellbeing today

	None of the time (1)	Rarely (2)	Some of the time (3)	Often (4)	All of the time (5)
I've been feeling optimistic about the future (4)	○	○	○	○	○
I've been feeling useful (5)	○	○	○	○	○
I've been feeling relaxed (6)	○	○	○	○	○
I've been feeling down, depressed or hopeless (7)	○	○	○	○	○
I've had little interest or pleasure in doing things (8)	○	○	○	○	○
I've been dealing with problems well (13)	○	○	○	○	○

I've been thinking clearly (14)	○	○	○	○	○
I've been feeling nervous, anxious or on edge (15)	○	○	○	○	○
I've been feeling unable to stop or control my worrying (16)	○	○	○	○	○
I've been able to make up my own mind about things (17)	○	○	○	○	○
I've been feeling close to other people (18)	○	○	○	○	○

If you are taking any prescribed **medications**, please indicate their names here together with the approximate time you took or will be taking them

_____

_____

_____

If you have any other observations on the day that you think may be useful for us to know, please note them here. This could be unusual events such as getting a promotion at work, changes in your lifestyle, or just a particular way that you felt today that we have not captured above.

_____

_____

_____

Finally, what date do your responses refer to? If you are recording responses from a day that is NOT today, tick 'Another day' and enter the date your log refers to (e.g. enter '29th May' for your wellbeing on the 29th May).

- ○ Today (1)
- ○ Another day (please enter date) (2)

_____

Appendix B

Interview Schedule

Background Questions

Do you currently have a diagnosis of DPDR, or have you recovered from it?

If you still experience DPDR, have you noticed any changes in your symptoms since participating in the dream diary study?

How frequently do you typically experience dissociation? / If you have recovered from DPDR, how often did you experience dissociation before recovery?

Experience of waking/dreaming sense of self and comparison

1. Can you describe the differences between your sense of self before experiencing DPDR and the one you currently experience?

2. Can you tell me what your dream life is currently like? Are there any dreams you wish to share?

3. Can you tell me about how you experience your sense of self when you're awake compared to in your dreams? *[follow up detail and time periods]*

4. Can you tell me about your experience of recovering an authentic sense of yourself in your dreams? *[follow up detail and time periods e.g. elaborate on a specific dream where they felt particularly connected or disconnected]*

5. Can you describe the way these dreams make you feel/impact on your current self and your experience of DPDR?

Understanding/meaning making

1. How do you make sense of (not) being able to connect with your former sense of self in your dreams?

2. Thinking about the context in which these dreams occur, can you tell me about any events in your life that seem to coincide with these dreams becoming more frequent or intense? *[Follow up re whether they think events could shaping the content and significance of these dreams]*

Reflection and Closing

Is there anything else you'd like to share about your dreams and your sense of self before we conclude this interview?

Thank you. Any questions?

Appendix C

Recruitment Email

Dear X,

I'm writing as you previously took part in a dream diary study which Anna Ciaunica and I ran in the summer of 2021. As part of this study, you gave consent to be contacted for future research opportunities.

I would like to ask if you wish to participate in a follow-up research project. The research is being conducted by Rebecca Shashoua, a Trainee Clinical Psychologist under my supervision. She is currently studying on the Doctorate for Clinical Psychology at the University of Essex. As a follow on from the dream diary study, **Rebecca would like to conduct a one-off, online interview (conducted via Microsoft Teams) in the early summer of 2024, to find out more about how you experience your 'sense of self' in your dreams and in waking life.** You will receive a £10 Amazon voucher as a thank you for your time.

I have attached an information sheet to this email, along with a consent form, explaining the study in more detail. Please take your time to read through the information and **if you would be happy to take part, please sign and email back the consent form to Rebecca (rs22890@essex.ac.uk).** Rebecca will then remain in contact with you from this point onwards for the study.

As very little is known about depersonalisation-derealisation disorder (DPDR), we would highly value your experiences and **you can still participate in the study, even if you have recovered or no longer have a DPDR diagnosis or symptoms.**

Whether you decide to take part or not, we would be interested to know how your symptoms of DPDR might have changed or stayed the same since the dream study. We would be grateful if you could let us know:

Do you still have a diagnosis of DPDR? If not, when did you recover?
If you still experience DPDR, have your symptoms changed?

If you have any questions before consenting, please feel free to email Rebecca with any queries.

Thank you for considering taking part and we hope to hear from you soon.

Best wishes,
Helge and Rebecca

Appendix D

Participant Information Sheet

Date of approval: 20th December 2023

What is the purpose of the study?

Depersonalisation-Derealisation (DP-DR) is a dissociative disorder marked by distressing feelings of unreality or detachment from one's self or the world. Little is known about DP-DR and the subjective experiences of people living with it, and even less is known about whether the symptoms experienced in waking life continue in dream-state. The subjective experience of "living in a dream" in DP-DR suggests that there may be permeable boundaries between sleeping and waking thought, therefore exploring dream content in relation to waking mental states is of great importance.

Results of a dream diary study which took place in 2021 revealed that some people with DPDR felt able to retrieve a 'true sense of self' in their dreams, which they had before their onset of DPDR. Others did not feel this was the case for them.

It is unclear what this experience meant to participants of the dream study, or their interpretation of it. Therefore this study aims to conduct follow-up interviews with participants of the dream diary study, to investigate the experience of being able to retrieve a true sense of self in one's dreams or not.

Invitation paragraph

My name is Rebecca Shashoua, I am a Trainee Clinical Psychologist and I am currently studying on the Doctorate for Clinical Psychology at the University of Essex. I would like to invite you to participate in a research study. Before you decide whether or not to take part in the study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please feel free to ask if there is anything that is not clear or you would like more information on.

Why have I been invited to participate?

You have been asked to take part in this study following your participation in a previous study, in which you completed dream diaries over a 2-week period in 2021. At the end of this study, you were asked if you would be interested in participating in future research and you indicated that you would be happy to be contacted.

The current project aims to follow up on this, and forms the thesis for my doctoral studies. The project hopes to gain a better understanding into people with depersonalisation-derealisation (DPDR)'s sense of self in real life and in their dreams.

Do I have to take part?

Your participation is voluntary and it is up to you whether or not you wish to participate in this research study. If you decide to take part you will be asked to provide written consent. You will be free to withdraw from the project at any time without giving any reason and without penalty.

If you wish to withdraw please email me. If any data have already been collected, upon withdrawal, your data will be destroyed if possible, unless you inform the principal investigator that you are happy for us to use such data for the scientific purposes of the project.

Please note that the destruction of your data following withdrawal will only be possible if you have provided us with information that can identify you (i.e.., your email address or interview recording).

What happens if you agree to participate

If you are willing to participate, please return the consent form attached to this email to me (e-mail rs22890@essex.ac.uk).

Upon receiving your signed consent form, I will email you back and ask you to confirm the email address where I can send the link for the interview, as these will take place via MS Teams. Interviews will be recorded as video files and stored until they have been transcribed on an encrypted hard drive.

The interviews will be an opportunity to discuss your experiences of your sense of self in your dreams and in real life, before and after your diagnosis of DPDR. Their length is unconstrained and so how long it lasts depends on how much you would like to expand on your experiences. Once the information has been transcribed it will be fully anonymised.

All information collected will be stored on the University's Box cloud storage and will only be available to the primary investigators. Anonymous transcribed recordings are stored in a separate folder to the raw recordings.

What are the possible disadvantages and risks of taking part?

There are no known risks to taking part. However, if you find the conversation upsetting, you are free to take a break or withdraw from the study at any time.

If you feel you would benefit from support from a charity or helpline, you may wish to consider:

- Samaritans: To talk about anything that is upsetting you, you can contact Samaritans 24 hours a day, 365 days a year. You can call 116 123 (free from any phone), email jo@samaritans.org or visit some branches in person.
- MIND: Mental health charity. Visit mind.org.uk for information about DPDR and support available in your area
- Unreal: a charity specialising in DPDR. visit unrealuk.org for information on support and resources available

It is recommended that you speak to your GP if you feel affected as a result of talking about your DPDR experiences.

What are the possible benefits of taking part?

By participating in this study you will be contributing to increased understanding of the impact of DPDR on people's sense of self. You will also receive a £10 thank-you voucher for your time.

Data gathered

- Name, age and ethnicity has already been collected in the 2021 dream diary study.
- We are using this data to provide anonymised context to people's experiences.
- Your data will be gathered by Rebecca Shashoua.
- Personally identifying data will be stored on an encrypted hard drive which will only be available to the primary investigators.
- Signed consent forms will be stored separately from individual experimental data on an encrypted hard drive which will only be available to the primary investigators.
- Your personally identifying data will be retained for as long as the research is being written. It will be deleted at the end of 2025.
- Our legal basis for processing your personally identifying data is that you have consented to it.
- The data controller is the University of Essex.
- Essex University's Data Protection Officer can be contacted on dpo@essex.ac.uk.
- Your data may be anonymised (so that you cannot be identified from them) and published in scientific journal articles, and shared in permanent, publicly accessible archives accessible from any country.

What should I do if I want to take part?

If you want to participate in this study please type your name and date into the consent form attached to this email and email it to me at rs22890@essex.ac.uk.

What will happen to the results of the research study?

The results of this study will be used for a doctoral thesis, as well as for publication. It is intended that the result of this study be used for publication in the public domain. However, any information presented in conferences or written publications will not be identifiable. The final publication of these results can be acquired through emailing me.

Confidentiality and anonymity

The data will only be accessible to research team to maintain confidentiality.

Ethical approval

This study has been reviewed by the Ethics Sub-Committee-2 and has been given approval with the following Application ID: ETH2324-0066.

Concerns and complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact me (Rebecca Shashoua), the Principal Investigator of the project. If you are still concerned or you think your complaint has not been addressed to your satisfaction, please contact the Director of Research, Professor Camille Cronin (e-mail camille.cronin@essex.ac.uk). If you are still not satisfied, please contact the University's Research Integrity Manager, Dr Mantalena Sotiriadou (e-mail ms21994@essex.ac.uk). Please include the ERAMS reference which can be found at the foot of this page.

Name of the Researcher/Research Team Members

Rebecca Shashoua (rs22890@essex.ac.uk) (Trainee Clinical Psychologist)

Helge Gillmeister (helge@essex.ac.uk) (primary supervisor)

Emilia Halton-Hernandez (e.halton-hernandez@essex.ac.uk) (second supervisor)

University of Essex Research Integrity Manager
Mantalena Sotiriadou, Research & Enterprise Office, University of Essex, Wivenhoe Park, CO4 3SQ, Colchester.
Email: ms21994@essex.ac.uk. Phone: 01206-873561

Appendix E

Consent Form

Consent Form

Exploring the Dream Continuity of Depersonalisation-Derealisation Disorder Symptoms

[Rebecca Shashoua (Trainee Clinical Psychologist) Helge Gillmeister (primary supervisor) Emilia Halton-Hernandez (second supervisor)

Please initial box

1. **I confirm that I have read and understand the information sheet for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily.** ☐
2. **I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty.** ☐
3. **I understand that an audio/video recording of the interview will be taken and transcribed into an anonymised text format, and that these data will only be accessible to the researchers named above.** ☐
4. **I consent to the use of anonymised direct quotations that I have given in my text-based responses in publications arising from this interview.** ☐
5. **I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained.** ☐
6. **I understand that my fully anonymised data will be used for a doctoral thesis and research publications.** ☐
7. **I understand that the data collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.** ☐
8. **I give permission for the deidentified (anonymised) transcripts to be deposited in or a research data repository so that they will be available for future research and learning activities by other individuals.** ☐
9. **I agree to take part in the above study.** ☐

Participant Name _____

Date _____

Participant Signature _____

Appendix F

Fraser (2004) prompts for data analysis

Phase 1 prompts

- What 'sense' do you get from each interview?
- How are emotions experienced during and after the interview?
- How does each interview tend to start, unfold and end?
- How curious do you feel when you listen to the narrators?
- How open are you to developing further insights about yourself, including insights that are derived from raking over past experiences that are painful?
- Do you have adequate support to engage in work of this nature?

Phase 3 prompts

- What are the common themes in each transcript?
- Are there 'main points' that you can decipher from particular stories?
- Where are the vocal inflections? What might they signify?
- What words are chosen and how are they emphasized?
- What kinds of meanings might be applied to these words?
- What other vocalizations and non-verbal gestures are present?
- What contradictions emerge?
- Are there notable silences, pauses or gaps? If so, how might they be distinguished and what might they suggest (for instance, disagreement, boredom, distress?
- Are there any other useful ways to disaggregate the stories and lines? If so, which form of disaggregation will be used?
- If stories are to be named as well as numbered, how are the names derived? Is the logic of this system made clear to readers?

Phase 4 prompts

- Are there aspects of the stories that highlight intrapersonal experiences that are concealed from others? If there are, what bearing might this have?
- Which parts of the stories relate to interpersonal relationships and interactions? How do they relate to the other aspects of the stories?
- Are cultural conventions – or transgressions to cultural conventions – evident? If so, what are the effects?
- Is there any evidence of popular culture emerging in the stories? If so, what is it?
- Are social structures – institutionalized or otherwise – present? If so, how do they appear and what is being said about them?
- If only one domain of experience is being analysed, what are the implications? Is this made clear at the start?
- If different domains of experience are to be made explicit in the analyses, how might they be linked?

Phase 5 prompts

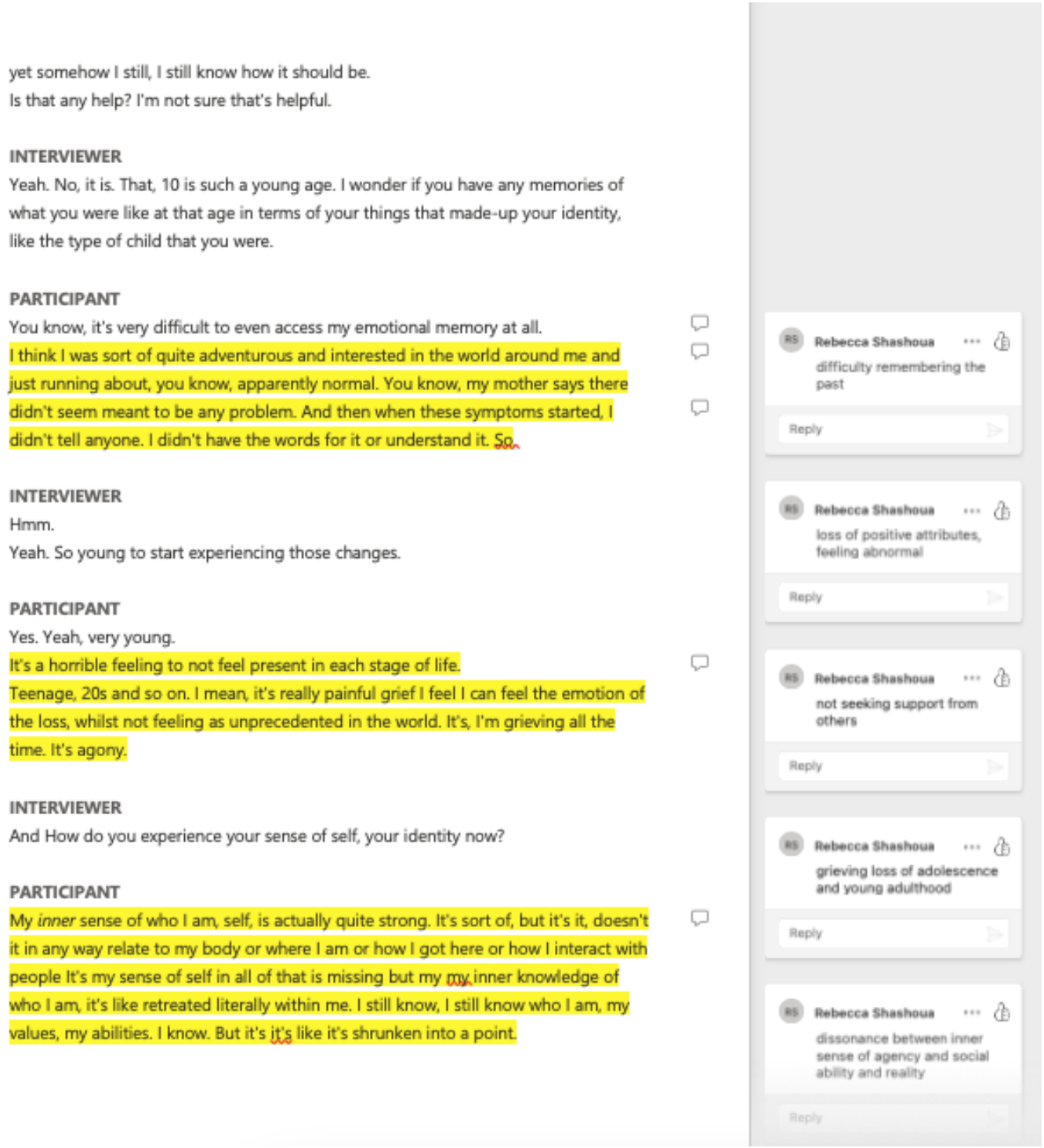
- What relationship do the stories have to particular discourses?
- How do you imagine other theorists are likely to analyse the stories?
- What might other social theorists say about the interpretations you have made?
- Do the stories support, negate or unsettle specific claims made about relevant discourses?
- Are there ideas raised that theorists/social commentators do not mention?
- What do the stories say about the (multiple) lived experiences of class, gender, race, sexual orientation, age, dis/ability, religion and/or geographical locations?
- Have you clearly distinguished participants' accounts from your own? Or are their accounts becoming too subsumed by your analyses?
- What responses might/do the participants make about your analyses? If there is disagreement, will it be signalled? If so, how?
- Are revisions to your analyses now required?

Appendix G

Example of coded transcript

Yellow highlight = narratives of constancy and change across time

Green highlight = narratives of agency



yet somehow I still, I still know how it should be.
Is that any help? I'm not sure that's helpful.

INTERVIEWER
Yeah. No, it is. That, 10 is such a young age. I wonder if you have any memories of what you were like at that age in terms of your things that made-up your identity, like the type of child that you were.

PARTICIPANT
You know, it's very difficult to even access my emotional memory at all.
I think I was sort of quite adventurous and interested in the world around me and just running about, you know, apparently normal. You know, my mother says there didn't seem meant to be any problem. And then when these symptoms started, I didn't tell anyone. I didn't have the words for it or understand it. So.

INTERVIEWER
Hmm.
Yeah. So young to start experiencing those changes.

PARTICIPANT
Yes. Yeah, very young.
It's a horrible feeling to not feel present in each stage of life.
Teenage, 20s and so on. I mean, it's really painful grief I feel I can feel the emotion of the loss, whilst not feeling as unprecedented in the world. It's, I'm grieving all the time. It's agony.

INTERVIEWER
And How do you experience your sense of self, your identity now?

PARTICIPANT
My *inner* sense of who I am, self, is actually quite strong. It's sort of, but it's it, doesn't it in any way relate to my body or where I am or how I got here or how I interact with people It's my sense of self in all of that is missing but my my inner knowledge of who I am, it's like retreated literally within me. I still know, I still know who I am, my values, my abilities. I know. But it's it's like it's shrunken into a point.

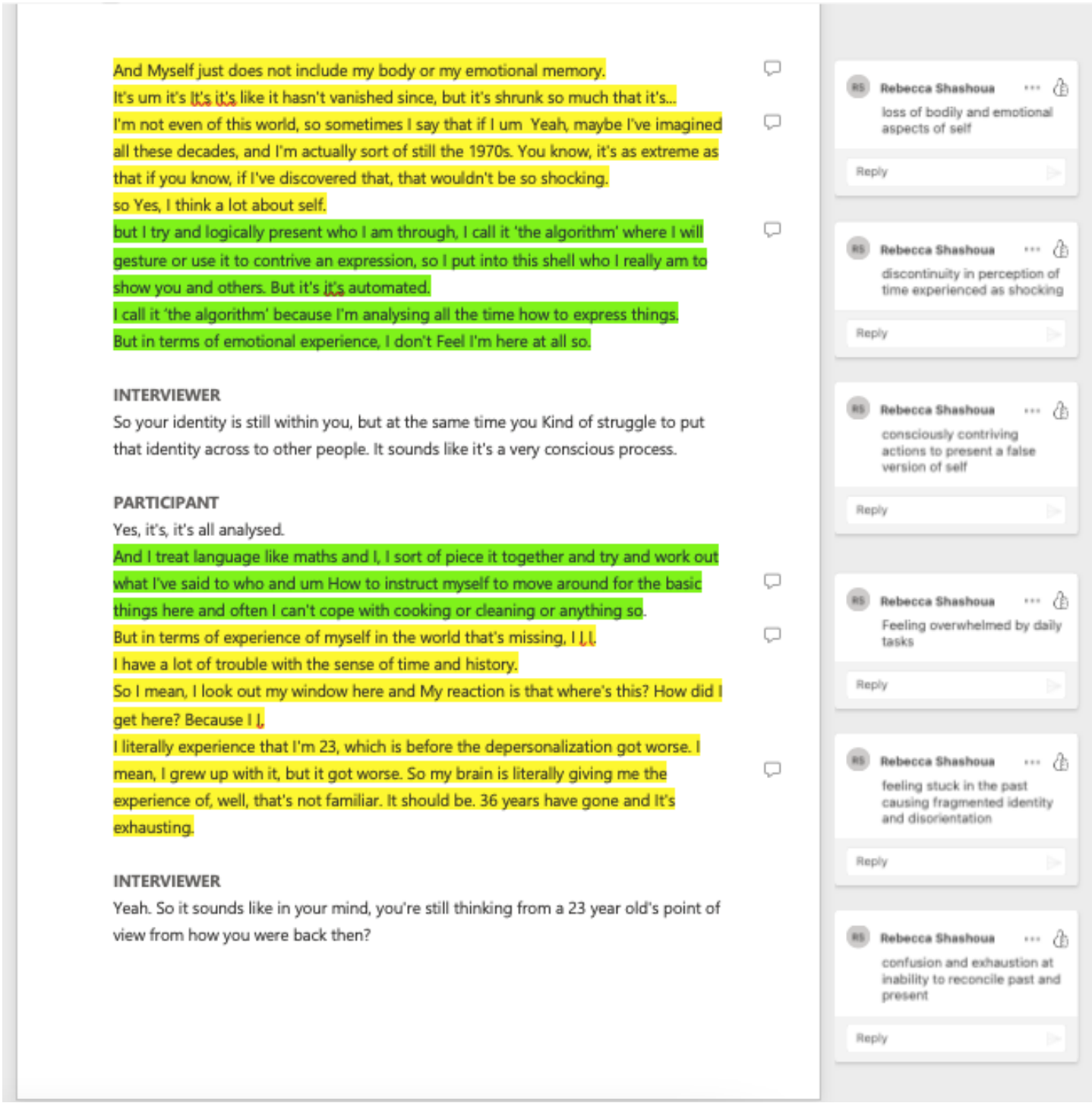
Rebecca Shashoua
difficulty remembering the past
Reply

Rebecca Shashoua
loss of positive attributes, feeling abnormal
Reply

Rebecca Shashoua
not seeking support from others
Reply

Rebecca Shashoua
grieving loss of adolescence and young adulthood
Reply

Rebecca Shashoua
dissonance between inner sense of agency and social ability and reality
Reply



And Myself just does not include my body or my emotional memory.
It's um it's It's it's like it hasn't vanished since, but it's shrunk so much that it's...
I'm not even of this world, so sometimes I say that if I um Yeah, maybe I've imagined all these decades, and I'm actually sort of still the 1970s. You know, it's as extreme as that if you know, if I've discovered that, that wouldn't be so shocking.
so Yes, I think a lot about self.
but I try and logically present who I am through, I call it 'the algorithm' where I will gesture or use it to contrive an expression, so I put into this shell who I really am to show you and others. But it's it's automated.
I call it 'the algorithm' because I'm analysing all the time how to express things.
But in terms of emotional experience, I don't Feel I'm here at all so.

INTERVIEWER
So your identity is still within you, but at the same time you Kind of struggle to put that identity across to other people. It sounds like it's a very conscious process.

PARTICIPANT
Yes, it's, it's all analysed.
And I treat language like maths and I, I sort of piece it together and try and work out what I've said to who and um How to instruct myself to move around for the basic things here and often I can't cope with cooking or cleaning or anything so.
But in terms of experience of myself in the world that's missing, I I I.
I have a lot of trouble with the sense of time and history.
So I mean, I look out my window here and My reaction is that where's this? How did I get here? Because I I,
I literally experience that I'm 23, which is before the depersonalization got worse. I mean, I grew up with it, but it got worse. So my brain is literally giving me the experience of, well, that's not familiar. It should be. 36 years have gone and It's exhausting.

INTERVIEWER
Yeah. So it sounds like in your mind, you're still thinking from a 23 year old's point of view from how you were back then?

RS Rebecca Shashoua
loss of bodily and emotional aspects of self
Reply

RS Rebecca Shashoua
discontinuity in perception of time experienced as shocking
Reply

RS Rebecca Shashoua
consciously contriving actions to present a false version of self
Reply

RS Rebecca Shashoua
Feeling overwhelmed by daily tasks
Reply

RS Rebecca Shashoua
feeling stuck in the past causing fragmented identity and disorientation
Reply

RS Rebecca Shashoua
confusion and exhaustion at inability to reconcile past and present
Reply

Appendix H

University of Essex Ethical Approval Email

University of Essex ERAMS

20/12/2023

Miss Rebecca Shashoua

Health and Social Care

University of Essex

Dear Rebecca,

Ethics Committee Decision

Application: ETH2324-0066

I am pleased to inform you that the research proposal entitled "Exploring the Dream Continuity of Depersonalisation-Derealisation Disorder Symptoms" has been reviewed on behalf of the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Appendix I

Example of one full interview transcript with researcher annotations

Note:
Highlights indicate analysis process and researchers thought about narrative type most dominant
Yellow highlight = constancy and change across time
Blue highlight = sameness vs difference
Green highlight = agency
Red writing = examples of my thoughts and reflections immediately after interview

Nathan 0:13
Hi, Becca. How are you doing?

Shashoua, Rebecca 0:15
I'm good. Thank you. How are you?

Nathan 0:16
Yeah, not too bad. Tired. Really tired. So. So I'm gonna be kind of like, method acting with the dream thing today. Not the best sleep, but yeah, cool. Thanks for like pushing it back to the afternoon like from earlier because yes, it's been full on at the moment. So it's nice to have a bit of breathing room.

Shashoua, Rebecca 0:35
Yeah, no worries. And thanks for offering your time as well and speaking to me today.

Nathan 0:40
No problem, no worries at all. Now it's nice to meet you. It's always good to meet people studying depersonalisation. That's great.

Shashoua, Rebecca 0:44
Yeah! and so before we get started today, I just wanted to double check that it's OK if the meeting is recorded?

Nathan 0:58
Yeah, no problem at all. Yeah, go for it. That's fine.

Shashoua, Rebecca 0:59
OK.
Perfect. It's just for my note taking and I'll need to look over the transcript of what we've said.

Nathan 1:07
Absolutely fine. Yeah, no problem at all.

Shashoua, Rebecca 1:10
OK.
Let me just double check that this is.

Shashoua, Rebecca stopped transcription

Shashoua, Rebecca 1:21
And I just want to make sure that's right before we start, because that would be awful if we ended and then it didn't record!

Shashoua, Rebecca started transcription

Nathan 1:26
Yeah, that's fine.

Shashoua, Rebecca 1:28
OK.
Perfect. OK. I think that's recording now.

Nathan 1:36
It.

Shashoua, Rebecca 1:37
So introductions! we've only messaged by e-mail, but my name's Becca and Helge, who you did the dream diary study with is my supervisor.

Nathan 1:38
Yeah.

Shashoua, Rebecca 1:51
I'm currently doing a doctorate in clinical psychology, so as part of that we have to do a thesis and yeah, I'm exploring.

Nathan 1:53
Amazing.

Shashoua, Rebecca 1:59
The sense of self in experienced in people with dpdr both when awake and when dreaming and any kind of like similarities or differences between them.

Nathan 2:03
Yep.
Hmm.
Sure. Fantastic.

Shashoua, Rebecca 2:13
So yeah, the style of the interview as well today is quite different from what I'm used to in doing research or in in general psychology with people, because it's quite open-ended and the aim is to kind of have minimal influences from me on your answers. So it's really natural for me to want to validate or give kind of snippets of my opinions on things. But for the purposes of this interview, I'm gonna try to not give my personal opinions on things. So if it seems like I'm being a bit cold or not offering answers that you would expect.

Nathan 2:52
OK.

Shashoua, Rebecca 3:01
Then it's the style of the interview! So I'm just going to be trying to follow your lead and there's no right or wrong answers, so whatever direction you want to take the questions in, I'll follow that.

Nathan 3:10
OK, fantastic. Cool, no worries.

Shashoua, Rebecca 3:14
Perfect. Do you have any questions before we get started?

Nathan 3:16
No, I don't think so. No, I think I'm all good. So yeah, whatever you want to ask, go for it. Not a problem.

Shashoua, Rebecca 3:19
OK.
Wonderful. So before I get into the questions, the Dream Diary study which you did, I'll just let you know a bit about that and what made me pick you out from that. So from the study, it

was quite evenly split into thirds as to people who felt they could retrieve that like authentic sense of self - so how they felt before the dpdr - in their dreams. So 1/3 of people felt that they could most of the time, 1/3 felt that they couldn't most of the time. And then a third were mixed.

Nathan 3:59
Yeah.

Shashoua, Rebecca 4:01
So based on that study, your answers were that you *could* retrieve an authentic sense of self in your dreams at the time, and things might have changed and that's fine.
So that's what some of the questions - when I'm asking about your sense of self in your dreams - that's what I'm referring to. But yeah, things have changed then just feel free to explore that as well.

Nathan 4:25
Will do. That's fine. Yes. I'll have to think on the think on the spot because things move all the time.

Shashoua, Rebecca 4:30
Yeah. And it was a while ago that that happened.

Nathan 4:33
Yes, a couple of years ago now, I think I can't remember exactly when it was good couple of years back, yeah.

Shashoua, Rebecca 4:36
Yeah. OK.
So sorry, I'm just going to stop the recording and restart it just because I've opened the chat and there is no transcription there for me.

◉ **Shashoua, Rebecca** stopped transcription
Nathan_Becca DPDR interview-20240429_143505-Meeting Recording
April 29, 2024, 1:35PM
1h 54m 17s

Shashoua, Rebecca 0:03
OK.

Perfect. OK. So the first question then, I was wondering if you could describe the differences between your sense of self before experiencing dpdr and the sense of self that you feel now?

Nathan 0:23
Hmm.
I think it's…
The comparison would have to be done with. I mean, so I wasn't aware of sense of self Pre-depersonalization, you know it was just something that was there, you know, you didn't even think about it. And it's since that stuff that can be chipped away that I've started to reflect back and have that point of comparison that kind of moves with time. So it's not something I've consciously thought about. I mean I just a bit of background, I started with depersonalization when I was 18, which was 2008. So it's been 16 years now or so, and my onset. It wasn't like a lot of people have it where it's like a sudden flicking of a switch or they wake up with it and it's just there and it's intense and terrifying. It was very much a slow sort of creeping in like a like a dimmer switch. Like, being sort of turned down slowly and it and it still kind of gets worse even now.

Shashoua, Rebecca 1:02
Yeah.

Nathan 1:20
So it's been like a 16 year kind of like fade out as opposed to a sudden thing. So it's changed as time has gone on and continues to do so.
So before that point, I wasn't aware of anything to do with reality. I wasn't. I didn't study philosophy or anything, you know, I was, I was. I was. No, I was a guitarist, as you can probably tell by all the rubbish piled up in the background. So I didn't think about anything to do with psychology or mental health or anything. But then as it's kind of got chipped away, I've had that point of reference, like you going back to and every time things get worse. I can think back and I think probably the biggest sort of difference was, It probably is that awareness That *something* is and has changed because before it was just there, it was constant. It was so invisible and transparent. You didn't ever focus on it. But my experience now is that I'm very aware that there's that metaphorical invisible barrier between me and the outside world, and I can have conversations with people. And I'm aware that noise is coming out my mouth and hopefully it's making some degree of sense, but I'm not consciously thinking about it. And I'm, I'm sure you've come across all the metaphors before, but it to me the most accurate is the 'it feels as if I'm drunk all the time'.

Shashoua, Rebecca 2:17
Mm hmm.

Nathan 2:34
That kind of two in the morning had way too much drink. You're sat in the bar. It's busy, but you you're kind of numbed to everything going on. You can look and you can identify things, but it doesn't *feel* real. Someone might say something and the words just come out and all that sort of stuff it's the autopilot completely estranged from reality feeling so I think that having that awareness, that something isn't right, I think is what's really changed and becoming aware that things are changing. And there's I, I guess the sort of nature of the sort of sense of self/ reality slipping away a little bit and that's that gets worse and worse, I focus on that a lot, but you can't *not* you know it. It's all the therapy teaches you that rumination is bad and don't monitor your symptoms. You can't avoid it when it's your daily life and it's 24/7. You know if all of a sudden things get worse. It's like oh, what's going on? What? What have I lost now that I didn't have? What don't I have now that I did have last year? What's changed? And you have to, you can't help but actually look at that and analyse it. So I think it's that that awareness of things changing and moving. I think that's my biggest change. I didn't even think about it pre depersonalization, I know if that went anywhere close to answering the question or not or just rambling on!

Shashoua, Rebecca 3:50
No, it definitely did! And you described that a process or you hinted at a process of analysing what's changed. Can you describe that a little bit for me?

Nathan 3:59
I think yeah, I can. I should say if, if I go off on a tangent and don't answer the question, please feel free to go, 'Actually the question was this'. Just remind me what the question was and I'll do my best to get back to it. Yeah, I think the way I've tended to describe how things have changed over time is it is kind of like a staircase. So I'm, this is my level of sense of self and consciousness and awareness and that that's how things are. And as time goes on, all of a sudden for what seems to be no reason, I'm sure there must be some reason somewhere it'll go [motions downward swoop] And that becomes my sort of new normal. It just suddenly drops and that's how things are. So I think I've become very aware of that happening and then all of a sudden I could be… I don't know I was out in the garden building a shed a few years ago of all things. I was there hammering nails in all of a sudden it's like whoa. It's like you've had a couple of shots and then it just hit you and you get that sort of 'whoa. That's strong' that wave is it and then that's the new normal it never goes back. So I think that's how things have gotten worse. It's that kind of incremental sort of drop, then another drop, 4, 5, 6, 7, 8 months on it, there's no fixed- doesn't seem to be any pattern to it so much aside from it's every few months there's this sudden drop. Whoa. And it takes. It's horrible for a couple of weeks. It's really hard to function because it does feel like you've had too much to drink and then you've had a few shots. It's like, 'oh, God, now I'm really trying-'. But you kind of like

acclimatise to it and you get used to it a little bit and then you kind of learn to function with those limitations, which is just about doable until the next time it drops and rinse and repeat. So I think that that's kind of what I mean by the sort of the worsening over time I think is that or staircase type sudden click of a switch and it's like, whoa, what's that? And it's like, it's like a wave of super DP as I tend to call it, but that that's the new normal at that point. It didn't never really moves after that.

Shashoua, Rebecca 5:51
Yeah, I'm. Can you, maybe thinking back to the last time that happened, describe the the instance of that happening and what went on for you?

Nathan 6:03
Yeah, I mean, I can't really remember any of the circumstances around it. It does seem to be random. Well, I've had 16 years of trying to sort of work out what the pattern might be and it's doesn't seem to be any rhyme or reason to it. I think it last happened maybe about sort of six weeks ago, something like that. Don't think there was any particular circumstances, but I can't remember where I was. Maybe I just woke up one morning or something. The last few months for me have been insanely busy because at the charity we're doing a big filming project. So I've just been pinging around like a pinball machine, Which is fun. I like being busy, but also nothing makes you appreciate your own bed like 3 months of travel lodges. It's just like oh god horrible so I think I've been really busy. Very burnt out like the last three weeks of the filming I was just ill like to have a cold or flu or whatever and just couldn't get enough rest in to actually recover. I was just always like as soon as I start to feel better, I had a long couple of days of filming and I'm back in bed again. Oh God. So I was burnt out. I was ill. I just wanted to be home and static for more than 48 hours and I think it was around that time and just as soon as I stopped that filming kind of got home and just went to bed, Everything kind of came crashing down a little bit. I think I was find that when I'm- I'm OK being busy, but as soon as I stop, that's when everything just implodes. So I think I had a bit of a mood crash around that point because our big project was kind of over and I was tired and I was just finally resting and I think it was around that time just kind of just was really struggling to function like just Remembering to eat, for example, you'd think that would be a simple thing. You feel hungry, you go make some food. But it wasn't it's it takes a lot of sort of conscious effort to go. 'That's what that feeling is. I need to go to the kitchen. I need to do this.' It's very clunky. So I was struggling just to get out of bed and eat enough food and just wasn't really being productive at all. I was like, you know, needing to be. But, you know, I would sit through an hour zoom meeting with like, a group of people. And I'd get to the end and go. I couldn't tell you a single word that was just said in that meeting. I participate. I remember saying things. I've no idea what anyone talked about as everything was just in one ear straight out the other. Even if in the instant I could react to words and say the right things, it was so….like living- It was like a goldfish memory, you know, I was living within those

few seconds and then it was gone. I couldn't tell you a thing, so I was just very much going through the motions and just everything felt very clunky and even like driving my car, which is always a weird thing with the personalization anyway But I was just like, wow, I really feel like I'm driving drunk. I'm not. And I know I'm safe, but I feel like this 'ahh, would I be able to react if anything happened?' and then when something does happen, you do react instantly and you know it's fine, but just everything has felt very uneasy and, like kind of wading through treacle, I think. And then you get to the point where you kind of just have to deal with it and go well, that those emails aren't going to answer themselves And that meeting's not going to happen if I don't chair it, And I've got some videos to make for clients. I've got to get that done because I know when the video has to be out and it's next week and I haven't done it yet. I mean, you just have to kind of force your way through it and then you start to kind of find some sort of equilibrium with it and learn to function with the new set of limitations. So I think I think that's, I mean it was it wasn't that long ago, a few weeks ago when that last kind of drop happened and it's never gone back. But I'm starting to kind of be able to actually type and speak and function a little bit again I think. Slowly!

Shashoua, Rebecca 9:42
Yeah.
And is there any connections with how that affects your identity and how you perceive who you are as a person that you can describe within that process. I felt this was open but I was conscious that I was changing topic as I wanted to steer him to talk about the impact of this experience on his identity. I reflected with my supervisors about this after the interview as I felt I shouldn't have done that, but we talked about the fact that it is ok and necessary to adapt my interview style. I'm not doing the FANI method strictly, but being informed by it, and keeping the question open ended to elicit narrative and follow on from the participant is still in line with that. Lightly steering the questions is therefore ok if participants speak freely and very much because I still need the contents of what they say to answer my research question.

Nathan 9:56
Mm hmm.
Hmm.
Yeah, very much so. I think over time, I, I I've kind of known who I am less and less I think. And I think even though pre depersonalization I wasn't a happy person at all and I'm still largely not, I don't think I kind of knew who I was. I had my interests and I had my way of doing things and it was I kind of had a fairly strong identity even if it wasn't one that other people liked. I knew what I knew who I was and then as time gone on, I feel like I've got more and more estranged from that and I there was basically like I've had it for 16 years, but last year was probably the worst year of my life by a long way. Some things happened. It was just a very difficult year. And I think as part of that, like there was a sort of triggering event

that just made me stop and look at how things were because I've been auto-piloting my way through everything so much and lots of the therapy I've had, including at like the maudesley in in London, like the specialist depersonalization disorder service there, Lots of the therapy seems to be focused on, I suppose productivity like increasing your productivity and distraction. It's less about actually improving the symptoms, it's more functioning *despite* the symptoms, which I would argue isn't particularly treatment, But you know, it's, that seems to be what the cornerstone is. It's 'you need to be more productive'. You know 'you've done 10 emails today, you do 15 tomorrow. That's it, You're getting better' and it's like, no, I'm just having.- I've just slept an extra hour and I can send a few more emails. Because they're that long doesn't really mean anything, you know.

And my symptoms are still worse. You know, that's… 'yeah but you're doing more!' so? I'm not happy, you know. And so I think a lot of the last sort of five or six years has been, ignore it. Pretend it's not there, just be more productive, take on more responsibilities, take on this job. Even though you typically wouldn't force your way through this, earn more money. Do that. It's all the sort of very, I suppose capitalist or productivity thing. But then last year happened and I just kind of had to stop and actually look at everything I was doing.

And I just kind of thought I don't know if I even have an identity anymore. I'm just doing what I've been told to do and what I've fallen into, and I'm just mindlessly going through the motions of things and yeah, it was kind of a scary thing to sort of step back and look at things and go. Why am I doing that? You know, I know I've always done that. I've done that for the last five years. But *why?* is that something I want to do? Is that something I have to do? Have I chosen to do this? Is it an interest? Are my hobbies even my hobbies anymore? Am I just doing things because that's what I do and am I actually get anything out of it? All those sorts of like, very reflective thought processes and um yeah I think last year especially was very much a realisation that my sense of self and my identity of who I am and it's really slipped, but because I've been distracting and just like being more productive, being more productive, the symptoms are carried on worsening in the background and I'd been kind of pushing through them and pretending I couldn't see it, and I think inevitably you get to a crossover point where your abilities and your commitments just come so far apart. You just explode. And that's kind of what last year was, I was just so far at my comfort zone and my capacity was nowhere near what it needed to be to actually do the things I was doing, and I just kind of imploded. So I think that was very much having to kind of really sort of hard reset myself and go right that strip everything away or why am I doing that? I have this way of doing things. Is that helpful or is that just the way it's always been done? and really look at what- who I am and my identity and you know what, I've always been a musician since I was young kid and that's always been my big hobby. I've always had the rockstar dream as a teenager, which obviously didn't work out, but that was always my thing was music, writing, music, playing guitar. But I still do video work for YouTube and like gear manufacturers. I do demo videos for them. That was always my big passion. It's like, am I doing that because I like it anymore or is that just always what I've done? Like just carried on that path without even

thinking about it? So yeah, I think that there's so much, you know, as I'm still very much early on in that process of actually working out who I am again.
Because it's so…I'm so estranged from that now, I think I'm it's so hard to kind of see through the fog and actually work out what's real and what are you doing and saying, because that's what you do, you know, and it applies to all areas of life, whether it's hobbies or relationships or whatever. You know, if you're in a romantic relationship, your partner says 'I love you' and you go 'I love you too'. Is that because I feel it and mean it? Or is that because that's what you do when you hear that prompt? That's it's like following a computer code: 'You hear this-you say that' Is it me or am I just Being robotic about this, I I don't know. So I think that's it. Yeah, it is. I'm still very sort of early on in that process of stripping everything away and starting to rebuild based on exactly who I am rather than who I think I should be or who I was before or anything. I think depersonalization is very difficult for knowing that stuff that you just *do*. And the therapy teaches you to just do. Don't think, do. And I don't necessarily think that's a healthy way to be going about living your life and trying to be happy is the 'just do' mentality. It doesn't really align with your values half the time I don't think.
I don't know if that answers any sort of question at all.

Shashoua, Rebecca 15:41
absolutely yes. So much information there, which is really helpful to follow up on quite a few things that you've said just there at the end there, you were talking about your values and aligning with your values.

Nathan 15:57
Yeah.

Shashoua, Rebecca 15:58
Could you tell me about those and that process of misalignment or alignment? In line with FANI method I was following on from the participants narrative to expand on it. The method says to follow on in the order of participants story but this was only my second interview and I was still not used to someone offering this much information and I was still finding the right balance of being able to stay present but take some notes at the same time. I relied here on recency but also my own conceptualisation of identity and feeling that the topic of values strongly relates to defining oneself. So my curiosity partly biased to follow up on this part of his narrative

Nathan 16:01
Hmm.
Yeah, I I think as I said earlier, I've, I used to have a very strong identity and then sense of what was right and what was wrong and who I was. And the way I wanted to conduct my life and all that sort of stuff. And then I think one of the things that depersonalization really does

to you as a person is it kind of it takes away the sense of consequences to things. And it very much is like the drunk mentality. You know, you have drinks, you act in a silly way because it takes away that sense of consequences. It's a similar process And it also makes you quite introspective in terms of analysing thought patterns. I mean, anyone who's been to any length of therapy is so conditioned to analysing thought processes and, you know, sense of beliefs and all that sort of stuff. So it makes you think a lot about how things might change And you look at behaviours and things you might do or say and you look back at it afterwards and go, oh, was that me? Was that me doing that? You know, that doesn't… That's not the sort of person I would want to be, the person who said *that* to that person, whatever it might be. Where did that come from? You know, why did I react in that way? So and so said *this* and I said *that* that was terrible and it makes you really think about your behaviours quite closely. And it can be really difficult at times because you feel estranged from the person who did those things well or said this, whatever it might be, it could be tiny thing. It could be a massive big mistake you've made in life, whatever it makes you kind of feel very detached from the person who did that, even though you logically know it was you.
And it does make me worry about how my personality might change over time and Am I becoming a person that I don't like, or is that just, you know, getting older? I don't know. You know, or spending time with people and you sort of absorb, it's their personality And that's what comes out And you don't like how it's been incorporated into your own, all that sort of stuff. It makes you very aware of that and very analytical of how and why things are happening or why you've reacted in certain ways.

Shashoua, Rebecca 18:15
Mm hmm.

Nathan 18:16
And yeah, I think largely I do still have fairly decent values and generally speaking align with the most of the time, but then you know if you ever make like a big mistake in life, you sort of look back at it and go like that… That's not me. I know it was me, but that… that… I wouldn't have done that. But I know I did, but it's, and it. And it's that kind of dissonance and disconnect between who you *know* you are and who you *feel* you are. It, it kind of, sometimes it's closer, sometimes it's further apart, but it never really meets whatever happens there's always that gulf in the middle. Where You don't really feel connected to yourself in the world and that you're just kind of floating and you know it's it's very difficult to actually feel that sense of consequences about things. So it is like trying to have a very serious conversation with somebody after being in the pub for 8 hours. You know, you're not good. You're just going to ramble and spew rubbish and say things that might be kind of overly honest, but you would normally filter it, but you don't. You just say it and then that upsets someone's like it's difficult because you're so numb from the alcohol. It's a it's a similar type thing with depersonalisation, I think.

Shashoua, Rebecca 19:29
You have a sense of feeling, like you said, kind of numb or not in control of what you're doing or what you're saying anymore.

Nathan 19:40
Hmm. I yeah, I mean it fluctuates and I think sometimes I can be fairly considered about the things I say. I mean hopefully I'm not rambling too much now, I know I tend to go off on tangents! but you know, I tend to be sort of fairly considered and OK at hearing a question and actually thinking about it and answering. But then sometimes you get that state - and I guess it's fairly normal for people to a point, but I think amplified for depersonalization - where you might be in the middle of a conversation or sentence And you become so very aware of your own voice. It's like, wow, that's *me* making that noise. What am I even saying? I don't have no idea what I'm going to say next, but the words just keep coming. And it's like, there must be a script or some sort of, you know, like auto queue or something. I don't know what's going on Like, words are just appearing, and they make sense, but I'm not- It feels like I'm not consciously thinking about them. I know I *must* be, but I feel so…
Floating above the situation and you know, I'm just here with noise coming out and I'm over there somewhere giving about 20% of my attention to what I'm saying. You know, I'm on my phone like 'Yeah, yeah, great', You know, but it kind of feels like I'm not really in the moment, even though I can smile when I need to smile and say things that make some sense. It feels like I'm not really giving life my full attention. Like, it is like you're trying to send a text message to someone and someone's talking to you. 'Yeah. Yeah. Great. Whatever'. Yeah. It it kind of feels a bit like that. But with all your life, you know, you're never really in it too much or thinking too much about the things you're doing. You just kind of float through when it happens.

Shashoua, Rebecca 20:59

Yeah. And that's how you feel all the time?

Nathan 21:16
Hmm. Yeah, it's for me. You know, some people get it where it's transient and episodic. For me, it's chronic 24/7. I haven't had a single moment of not feeling like this to some degree in 16 years and it doesn't really move around too much on the sort of monthly basis, I don't think. It's always there. Some days are harder than others, but it tends to be the sort of, I think, cognitive loading of you've got the baseline- if the screen is my capacity [motions hand to be at the top of the screen]
If that makes any sense, I'm always right at my limit, and then if I'm stressed or tired, it kind of bumps me above that and I really struggle to deal with it all. But the depersonalization is

fairly static, it just takes up most of my ability to deal with things really. So any minor stress or minor exhaustion or minor overload or whatever, that's a problem. You know, I'm very limited in my capacity most of the time I think. Certainly with the fatigue, I think especially.

Shashoua, Rebecca 22:17
Yeah, and you described within that feeling a change in your personality over time. Is that something that you can describe to me? that change?

Nathan 22:31
Yeah, kind of, I think I've become more honest over time, which is I suppose, can be a good and a bad thing, and I think I've become much more accustomed to verbalising not necessarily how I'm, I suppose, how I'm feeling to a point, just feelings are very numbed down, but I'll tend to be very ease of analytical and reasoned about things, but if I still come to a conclusion, I'll tend to *say* it. And I've all I've tried over the years - where I feel so removed from everything - to act more instinctively in the moment, which again can be a good and bad thing, but also be sort of very reasoned about things, and if, if especially in like a relationship context, if I'm sat with my partner and I sort of feel something, I'll say it, you know, I just kind of want to verbalise it rather than bury it and go, oh, I should say that or I want to say that, but it might be a bit cheesy. I'll, I'll just say it And I've kind of become quite used to being a bit more impulsive. not necessarily in a bad way, And just be more honest about things.
But yeah, I think it's also it's very difficult to feel enjoyment from *anything* really.
So and I've always been someone that's kind of liked the, I suppose extremes of things with anything like, even if I'm cooking, I like strong flavours. You know, I don't want anything bland and I want to, you know, if I'm going to add some chilli and I'm adding a lot of chilli and burning my head off, you know, I kind of go to the extreme on things. if I have a guitar and I'm changing it up and messing with the electronics, I'll make it as good as I possibly can down to the type of solder I choose. You know, it's really nerdy, it there's no- it's very, it's a perfectionist trait. I think people are often identified in me and a lot of people with depersonalisation. I think that's very true. If I'm working on something I'm, I've, I've re-recorded entire songs before because I thought of a slight change to a chord no one would notice. It's not going anywhere aside from on YouTube. It's not getting released. but I know so I have to go back and make it perfect in my mind and I think that's definitely Become stronger slash worse depending on how you frame it over time is, I don't think I'm ever satisfied with anything. I think that's a lot of the problem, whether that's me, the condition or both. And obviously they're linked. I think it's very hard just to feel Happy and satisfied And the sense of achievement, I think is another big one.
It's very hard to feel like if you achieve something, like *you* have achieved it. It's just a phrase that someone might throw around. I remember when I was at university, it was kind of the early years of depersonalization, very difficult in what was going on. The usual sort of stories

people tell thought I was, quote, "going crazy" and all the psychiatrist appointments, really struggling with limited capacity, having to study, absorbing information, tired all of that and I sort of battle through it, nearly quit after two years, forced my way through, did the third year and I remember going into the office of the guy who ran the sort of college university, and he was like 'I got your result'. You know, 'well done, You got a first for your degree'. I was like, OK, cool. Can I get back to work now? You know, *nothing*. Three years of really hard, very big struggle of really working as hard as I could. And I managed to get the top grade and it was just like, OK, I'm in the middle of recording something in the studio. Can I go back now because it's slowed me down. Couldn't appreciate it at all. And I think that's Definitely something that's gotten worse over time And I think that almost makes me a bit more sort of blase about things sometimes. So it almost, I suppose maybe it helps the perfectionist stuff 'cause. It's like, well, no one's gonna care. And I don't care. So just do it. You know, you can become a bit more flippant about how you do things Because becoming so estranged from the sense of achievement, you know, A couple of weeks ago I ended up down in Lisbon. I was talking at a conference down there and talking to a crowd of people about depersonalization standing up and got to the end of it. OK, cool. Can I go home now?
That's quite-. If someone doesn't do public speaking for a living, that's quite a big thing to do is travel and talk at this thing. Cool. Yeah. Can I just go and have a beer now, please? That'd be nice. You know, just no sense that you've just done something that was good and out your comfort zone. You've pushed and you've achieved it, and it's gone well, and people are asking you questions and it's positive.
Great. Go on for the next thing. You become very used to the sort of grayscale life I think. So I think that's another sort of thing that's definitely changed for me is things become more grey. So you become more estranged from that sense of achievement and you find yourself in some areas of pushing *more* to the extremes. It just to try and feel things and experience things and just try and get *anything* out of an experience that you can because it's it becomes more and more numb. So you have to kind of try harder to get anything out of it, so I think I'm I've maybe come a little more, I don't know what the right word is, I don't wanna say extreme in my behaviour 'cause That really isn't the case at all. I'm very tame most of the time, but I've become a bit more kind of Eager to push things to the limit to see if I can get anything. I know what I will experience, so if I push that a bit further and Stand up in front of *that* many people and talk. 'Do I feel anything?' 'No', OK well what can I do next time is different Then to make it next level up? And I guess the perfectionism and the pushing to the extremes and all of that- I'm not sure exactly how it's changed my behaviour so much, but it's that that's definitely part of the thought process behind things for sure and becoming more sort of flippant about things you do and say it's- none of it matters and none of it's real So whatever. it's that sort of drunk feeling.
Similar to Wilana and Daniel's narratives about pushing boundaries?

Shashoua, Rebecca 28:27

Yeah, that real contrast between the side of you, that's being more flippant about things And then the side of you that's wanting to be the opposite and more perfectionist about things and controlled about things.

Nathan 29:02
Mm hmm.
Yeah.
Yeah. Yeah, exactly. There's and I think that's certainly something I've become aware of. When Was it? I wrote a book about depersonalization a few years ago, and one part of that was I was interviewing – it was in the middle of COVID so all those interviews were on zoom - and there was a psychiatrist, I think in the states that I interviewed And she said that for her and her experience, a lot of depersonalization is caused by, like, a mismatch *within* yourself. So essentially, the protective mechanism that happens in trauma, a lot of the time- it you're trying to protect yourself from yourself.
Something doesn't line up and it's kind of pulling yourself apart a bit, and I've thought after that I've become much more aware of those sort of contradictions in my personality and I think that's a very good one. Like everything has to be right and perfect and done as well as I possibly can, but equally it feels like nothing, I couldn't really care less about it. So meh and where's the middle ground and if you find a middle ground, neither party is satisfied. So do you go to one extreme or the other and neglect that side of things? But at least the perfectionist side is covered because it's done properly or… you know there's a lot of those sort of mismatches and sort of Dissonances within my personality. I think that I struggle with and say I've definitely become more aware of aware of that, like how things don't necessarily line up with other parts of who I am and where that might have come from in terms of psychology and parents and friends and all that and where where's that come from? That's definitely been on my mind a lot in the last few years I think.

Shashoua, Rebecca 30:15
Hmm.
Yeah. And this sense of self that you have when you're awake now, living through depersonalization, can you explain how that sense of self compares to the ones that you feel in your dreams? – Another change in direction. I knew that I could have followed up more on this narrative but I was worried about time because of how much information I was being offered and the amount of questions I knew we had left to get through. In the moment, I felt at this point I had enough information about his sense of self when awake to add to the narrative types that it was ok to ask about dreams so that they could be compared

Nathan 30:42
Hmm.
It is a tricky one because I mean I do dream. I think everyone dreams, but I don't tend to

remember dreams very much and I think one of the one of the things I remember about doing the dream study before was I was on a medication at the time, It might have been a note of the study, You might be able to tell me what I was on, I don't remember, But one of the side effects of those meds, whatever they were, was it made your dreams really vivid. So I had the most ridiculous dreams for like, this two-month period that happened to be when the study was. And I remember waking up at like 3 in the morning and writing down what I just dreamt like 'I can't write now, That's crazy!' But then it kind of went. So I don't tend to remember things too much or how things are in dreams, but I think generally speaking, myself In reality and in dreams, it feels very similar To- or, it certainly does Nowadays, I can't remember what I wrote two years ago, but it does nowadays - It feels quite similar to when I'm asleep but I don't think I'm aware of depersonalization being a thing in my dreams, so I think the overall experience of things kind of happening, and it's all a little bit hazy and detached, and you're not really part of things, It's a similar experience, but in reality I'm very aware that that it is wrong and I'm feeling very estranged and very distant and very hazy and clunky and all those, all those adjectives. But in my dreams I'm a bit more kind of *in* it and it feels the same, but I'm not thinking about 'wow. I feel weird and I feel like I've been drinking and I feel like I'm stoned' or something. I don't think about that in dreams, even though the experience is very similar. So I think that that's probably the big difference that I've been able to identify over the years is, I think I have depersonalisation in my dreams, but I'm not *aware* of having it. Whereas in my daily life, even it's, it feels the same, but I'm aware Is quote "wrong" to feel as hazy as I do I think. so, but it's a broadly similar experience I think. Certainly nowadays it might have changed in the last few years. I can't even remember two months ago right?

Shashoua, Rebecca 33:04
Hmm.
Yeah. And I know you said that your memory is not very good for dreams. Is there anything from any time period that comes to mind that you could use as an example of the time that you either did or didn't feel depersonalised and what that was like?

Nathan 33:26
I I think.
One thing I do remember about doing the dream study, and I think I became aware of it then, I think it's been largely true since then I have remember little fragments of dreams. Just I guess as a slight aside is a lot of the difficult life experiences and traumas and negative self-beliefs and all that sort of stuff that a lot of people have said is probably contributing to the depersonalization came from my time at school. And I remember when probably medication induced when I was having lots and lots of dreams noting them down and really trying to remember what I dreamed.
It was a very much recurring theme that I was back at school and I just always kept being

back in that situation and that environment And I think that has been quite- whenever I have remembered fragments-, a lot of it does still centre around school.
But back then, I didn't have depersonalization, and yet I still feel the same way when I have those dreams, I think I still feel very estranged from things. So I guess that's you know, the dreams are very much influenced by the present day in terms of how I feel because I didn't feel like that at the moment, but you know, maybe that's just a dream thing. But yeah, I think in terms of- I'm trying to think of recent dreams I've had…
God, I can't even remember. I need to be honest. Like I occasionally wake up and think I've just had a dream and I can remember, but it's gone so quickly and like, forget about it. I can't honestly remember the last time I had a dream and remember anything about the experience, you know, at all.

Shashoua, Rebecca 35:10
Hmm.

Nathan 35:15
No, I can't. sorry it's not a good answer. Yeah, I feel so…It goes so quickly, I just can't remember What I dreamt about when I dreamt about it, how I felt in that dream or *anything* like it's just gone.

Shashoua, Rebecca 35:32
Yeah, dreams are really tricky things to remember a lot of the time. but I was really interested by what you said there when you were describing dreaming of yourself at school but feeling the way that you do now or I'm not sure if I understood that right. And I was wondering if you could explain that concept, that experience. Even though he said he struggled to remember dreams I thought this was an interesting experience that he could expand on that still answered the question of what it's like to be depersonalised or not in dreams

Nathan 35:38
Hmm.
Yeah, I I think me in the dream feels like my current experience of reality but the situation I'm dreaming in and the people who are in that dream that I knew 16 years ago and haven't spoken to since, for good reason, in those situations and those buildings talking to those people, I, the experience of being in that dream and interacting with those people in those environments feels like 2024 Nathan going down the shops to buy some food.
it feels similar, but at the time when I was for real in those environments, with those people I didn't have depersonalisation, so I think It's probably… obviously inspired by previous events and situations and people, but with a *current* experience, even though those sort of things happened 16 years ago, I don't know if that is describing it in any way that makes sense, but

it's the experience of my reality *Now* is the same experience of me in that dream that I'm having now. But it's kind of about 16 years ago when I didn't have DP. So I think I still have the same Experience of interacting with people and Speaking in the dreams 16 years ago, even though they're happening today, it's so hard to explain what I'm actually mean.

Shashoua, Rebecca 37:22
Yeah.
So your identity, your sense of who you are, it doesn't change in your dreams. That's you Now. Even when you dream of the past, you feel like you *now* rather than being able to feel how you did before the dpdr. – This was more closed but necessary for clarification and still following up on what he said

Nathan 37:43
Yeah, I think so. I think it's very much the current experience applies to dreams regardless of the situation or the time period in which that dream is inspired by or is kind of happening in because I'm that age or those people are there and in those buildings that I know where I was at that time, it was 2008. But I still feel like it's happening today with the current experience of reality, even though it's, Kind of I, I suppose, 16 years ago in terms of framing, I think, yeah.

Shashoua, Rebecca 38:15
Yeah, yeah. And can you describe the way that, that type of experience makes you feel or impacts you?

Nathan 38:29
of the sort of the self experience in the dreams? [I nod]
Not really…I'm trying…I think it probably makes it feel less real Because back then, when those people were in my life and I was in those environments, it was very real, you know, it was horrible, like enduring lots and lots of bullying for about 13 years or so in all of those, because I was in the same group of people for 13 years and they didn't like me and I didn't like them. So it was horrible being in that actual situation up to 2008. Whereas now They're not the sort of dreams that stay with me. I don't know and maybe that's part of the thing that because I feel so estranged from the self in that dream and I feel so estranged from myself In reality, it's so unreal that it just kind of goes. It's not like something that's particularly impactful and you know, you have those dreams that really stay with you and they bother you for however long afterwards. I never really get that even if it's like a bad dream verging on a nightmare which is rare I think.

Shashoua, Rebecca 39:35
Hmm.

Nathan 40:02
It it doesn't really have much of an impact because I'm so Removed from The Reality of what's going on, even though I logically know it's a dream and it's not currently happening and it's not real, it doesn't even feel particularly real in the dream in the moment I think so I think it may be as less impactful and it's probably part of the reason I don't really remember them because they're just so forgettable. You know, even if they would ordinarily be something that would kind of bother someone or you think back to something that actually happened and you're kind of reliving it and that's a difficult thing to have to kind of replay in your head, it just kind of goes because it's not having any emotional impact or, I feel like I'm going from one second to the next second, even in a dream. So it just kind of in one ear out the other and wake up 'oh That happened' and I've forgotten what it was get on with my day and off I go. So I think it may maybe it has less of a lasting effect, Dreams, and it becomes easier to forget what happened because it feels so unreal Even when immediately after you wake up, it's like, oh, what just happened?
it's it's confusing almost. It doesn't really sit with me too well.

Shashoua, Rebecca 41:16
Yeah, it do-. You say it doesn't sit with you too well?

Nathan 41:19
Yes, yes, as in like it doesn't sort of feel like it's having an impact. So it doesn't kind of stay it just kind of goes it doesn't sort of hang around in consciousness and emotions or feelings of reliving traumatic events and things. It just whoosh off it goes.

Shashoua, Rebecca 41:38
Hmm, that sounds really similar to what you described when you were describing your current sense of self in day-to-day. That feeling of just going through the motions. – making connections to previous answers. This felt like more of a therapy skill rather than FANIM technique but it was instinctive of me to do this and I didn't really think before saying it. in hindsight I'm aware this is my own reflection and interpretation, which I said I wouldn't do in the interview. Perhaps this doesn't really follow the FANIM principles because I'm steering the direction and connections being made, it is something I want to be aware of for future interviews to try avoid. Maybe I could have followed up on the 'feelings and emotions' he mentioned, but at the same time I felt unsure because I thought this would start a conversation about re-living traumatic events. Given how much he expanded on his answers, I was worried this could divert the conversation too far from my research aims, whereas this brought it back to focussing on identity as previously discussed

Nathan 41:45

Hmm.
Yeah. Yeah, exactly. And that's what I mean, I think the experience of dreaming is Broadly the same as my current life experience nowadays and Yeah, it's very hard to kind of think back to what I did yesterday and go well, That happened. it's easier to kind of think back and remember things and because there's other people to jog your memory on things. And 'oh do you remember doing that last week?' 'Oh, yeah, I do'. Obviously that doesn't really happen with a dream you've had yourself. But yeah, I think it is broadly very similar. Like it's that kind of goldfish memory type thing. You're in the sort of five second window and it moves and it moves, And what's over there whilst you were in the moment, you could respond properly in a not particularly clunky way, It's then moved on and you can't really remember it and you can't remember what you said. You can't remember what the topic the discussion was you're kind of existing within that small window and the whole window moves and I think that's kind of very similar to dreams I think.

Shashoua, Rebecca 42:53
Of things just moving on?

Nathan 42:53
Certainly for me.
Yeah, like you exist within a very short period of time and things that happen before that short period of time, You can loosely remember them, but they don't really have much of an effect. I mean, occasionally things do stick around and have a much bigger effect, but they have to be very extreme things to actually have a wider spread in terms of impact. Most of the time, In terms like daily things going to the shops, you know, driving somewhere, filling your car up, whatever it is, It's within that very small window and anything outside of that is so distant now that I might be able to remember it, but it's not *my* reality.

Shashoua, Rebecca 43:39
Yeah.

Nathan 43:40
Logically, I know it is, but it doesn't *feel* like my reality doesn't *feel* like anything did filling in my car up two days ago. I kind of remember where I was. Which garage I was at using the pump. But OK, I've got a full tank and I must have done it. You kind of… it goes very quickly. Your sense of actually being immersed in that action and that situation, it's very, very hazing. Now to the point, it's almost not there. I think that's like, loose memories of things you did.

Shashoua, Rebecca 44:08
Yeah.

And you were saying that some things stick with you and have an impact. Is there anything that you feel comfortable describing there?

Nathan 44:22
Yeah.
Yeah, I think the very obvious one in my mind was everything from last year. And I'll give you the crib sheet version. It was basically I had been in the relationship for about 6 1/2 years. So very sort of long term. Was becoming harder and harder and Getting more kind of, hmm I'm not sure that it's working, but I stuck with it.
And essentially what happened was I got too close to somebody else, and that all kind of exploded on me, as I fully deserved. But the sense of Shame, guilt, Everything that came along with that massive explosion Flawed me and it really affected me bad and still does in all honesty. It was over a year ago that all happened and it, and it still does affect me badly in terms of self-beliefs and That's kind of what I was meaning earlier about like behaviours and almost becoming a bit more blase about sense of consequences. Like I'm not the sort of person that would do that, but I still did And I have to come to terms with the fact that that doesn't align with my values in the slightest. You know, I'm, not that person And yet I still behaved in that way.

Shashoua, Rebecca 45:34
Mm hmm.

Nathan 45:46
Why? Where did that come from? Because I would never imagine a million years I'd be the sort of person that would let that happen, and it still did. Why? And that's where it's like, is my personality changing? Am I becoming a terrible person? And all of that stuff? And I think that was that was the thing that made me sort of stop and look at my life and go what is actually going on here? I know what I've been told is going on and what I've been trying to ignore is going on. What? Who am I? You know, where do my values lie? Where do my beliefs lie? what are my behaviours? What's causing them? I don't know and I think that's probably the biggest thing
I've Probably ever had, I think in terms of it having a huge impact, that just won't go away. And and I've, I've I've lost members of my family that I was very close to, you know, a few years ago my I still live with my parents just because for financial reasons I can't really have enough capacity to work to actually support myself reliably. My grandma lived with us for about 3-4 years, helping to look after her. She was 91 and she died. And I remember standing in the crematorium and my brain was singing Nelly the elephant.

Shashoua, Rebecca 47:02
Hmm.

Nathan 47:03
Everyone around me is like sobbing and it's very sad and I'm sort of like.
OK. She's got old and died. I can accept that. It's logic. I mean, that happens. Cool. OK, next.
And it's so… it makes it almost fit. You feel guilty because of how removed you are from any emotional response to that. It was just completely shut off. And yet when *I* did something spectacularly wrong, it just crushed me. And it still does. And it's so… it just worms its way into everything. And it just you think you're doing better and you just you just get side swept and you're in bed for days with it. I just can't Seem to seem to get over that at all.
So I I think that that's the best example of something like a major thing having a much deeper, Wide-ranging impact and it… but i suppose I mean the way I've tried to frame it in my mind is It's possibly a positive in some senses, despite the horrible things that happened. It's affected me emotionally and I feel like I don't have emotions, but *something's* going on because a couple of times last year I cried. I haven't cried in 16 years and yet something… there's still something going on in there. I was still affected enough and when it was happening I didn't feel sad. It was just happening and it wasn't even like a little tear. It was like proper ugly crying, you know.
And I was like, where's this coming from? I have no idea. I'm so confused because I don't feel sad or upset or anything at the moment, but this is happening and it. But that's why I've tried to frame it. Is like there's still something in there. Something was able to kind of get through the fog of the depersonalization and actually impact me. It was horrible and still is, but it's something. That's how I've tried to kind of flip it on its head a little bit that there was a bit of a positive in there somewhere that there was an emotional response to something whatever that was. So yeah, I think that's the best example of something really having a big lasting impact on me and I think.

Shashoua, Rebecca 49:09
Yeah, it sounds like it made you re-evaluate who you are, which you were questioning

Nathan 49:15
Yeah.
Yep, yeah, I was questioning it for ages and then Something happens that is just so out of character and so unbelievable in terms of values and morals, and all of that, and you think how the hell did that happen? And it makes you really stop and sort of go well. I mean, obviously like that happened. I, I was the one who did that. And I can blame it on an illness. I can blame it on being drunk, which I was but I'm still responsible for that. That's still on me and all sort of suffering. I still kind of deserve that based on what I did. So where did it come from? How did that happen? You know, it feels like something that somebody *else* would do, but I know that was reality and it's uncomfortable. It's really, like, deeply and sort of intimately uncomfortable that that happened And I did it, and it just doesn't feel like even

conceivable that that would ever happen to *me*. And it did. And it's, it, really I suppose kind of shocked and traumatised me in a way that I was capable of doing *that*. Because it's just not me. But it still happened. I've had to all the sort of beliefs that I've, you know, when I've heard of other people doing similar things, the sort of the judgement I've applied to them internally, I still believe that. But I now have to apply it to *myself* and that's just the worst for lying in bed in really dark head spaces, just ripping yourself apart because.
All the sort of suffering that's come since then for me, I feel I deserved massively.
But it's uncomfortable, But it happened and I allowed it to happen and I didn't spot that it was happening until it was too late. And where did that come from? It's really it's really affected me, I think. In quite an extreme way

Shashoua, Rebecca 51:11
Yeah.
And it sounds like the main thing since having dpdr which has made you question your sense of who you are.

Nathan 51:27
Definitely. And I think there's been similar things on a much, much, much lesser scale.
At different areas of life now you might someone might get angry with you and you respond by saying something hurtful. And it's like, wow, why did that come up? There's been much lesser extent, things like that have happened. That's where the sort of the thought process kernels have come from. But it was last year that just blew it apart and just made me kind of Question everything about myself and just literally have to strip everything away and start from complete baseline in terms of OK, what do I like to eat? That's a very small thing in the grand scheme of life, but I don't even know anymore. I would say I like pizza. I eat a lot of pizza, but do I actually *like* it? I don't know anymore that it makes you question literally everything from the ground up. And yeah, I think it's the most extreme Thing, since having depersonalisation, it's really Kind of taken those smaller bits that have been kind of creeping in over the last few years and just gone bang and blown it apart and it really kick started that process in quite a brutal way for me I think.

Shashoua, Rebecca 52:41
Yeah, questioning not just big major things like values, but those really small details of what makes a person who they are like this. They're small likes and preferences for things in life.

Nathan 52:53
Hmm.
Yeah. And literally everything, think things that most people would think are just completely pointless, you know, easy example and a very silly one, These are the plectrums I play the guitar with. I've used these since I was about 13 because they're cheap and they work at their

fine. They're the right thickness for me. All the sort of stuff that... Why? Why? do I even like these? Do I want a different one? would another one be more suitable? And it's something as small as a piece of plastic and apply that to literally everything up to who am I? What are my values? It's the entire scale down to the tiniest piece of yellow plastic on my desk. You know, it's it's everything. Why? Why do I do things the way I do them?
I'm A bit of a plane nerd. Do I actually like that? Why? Why do I have an interest in reading about how planes work? Why? What is it? Do I actually find it interesting? Or is it just a sort of thing to pass the time and have a bit of noise going in one ear and out the other? I don't know. So it's really, yeah, it's literally everything from the big life questions down to little pieces of yellow plastic on my desk.

Shashoua, Rebecca 54:09
Yeah. Yeah. And that sounds very, very different to how you described from what you could remember of your dreams and how you are and the kinds of thoughts that happen in your dreams.

Nathan 54:23
Yeah, I think, I mean, I think the dreams that I've had are very Restrained to the situation that's occurring in the dream that they're in that moment and there's nothing particularly far reaching about them. It's not that I have a dream about something difficult that happened at school and I wake up and I go, oh, I feel really terrible. Like what? Why did that happen? I, and then the kind of analysis begins. Never really happens like that. It might be a tricky thing I'm dreaming about, but as soon as I wake up, it's gone. It doesn't really have any lasting effect, whereas In the here and now, certain things have a very extreme lasting effect on me, I think.

Shashoua, Rebecca 55:06
Yeah. Is there any effect in the here and now of the dream that there is that maybe it doesn't last once you wake up, but in the moment of the dream? – This could have been worded in a more open-ended way. "can you describe any effect…".

Nathan 55:22
Possibly, but not that I'm really aware of. I don't think. I think the closest I might come to that is if you ever do have like a nightmare and you have that kind of sudden waking up like something happens in the nightmare and wake up in your bed that there might be a sort of cold sweat type thing going on. So there's some sort of effect happening, but it has to be very extreme and Like a certain difficult memory, or really violent or something. I don't know. It has to be very to the limit In order to have that effect, and it's, I wake up, it's like 'whoa' And it goes. So I think it's not something that even in the moment in the dream, I feel particularly

strongly about. So I'm not feeling upset or feeling angry in the dream, even though I'm I might be going through those motions, but I guess it's kind of similar to a lot of daily life.

Shashoua, Rebecca 56:16
Yeah.

Nathan 56:17
when you came on the teams call. I smiled. What? Why? Why did I do that? You know, it wasn't a conscious 'hi'. It just happened. So there's something happening. I'm responding and doing the sort of the social cues, but not consciously.

Shashoua, Rebecca 56:33
Hmm.

Nathan 56:34
And not sort of based in emotion or response or anything. It just happens by exhibit. You know, if I watch a comedian, I'll laugh. I'm not really feeling like it's funny, but I'm laughing. But I'm laughing. So it's something is happening somewhere. I think that's kind of like the in the dream as well. I might be in the moment and experiencing something, but it's not a strong reaction Unless it's that waking up suddenly like 'Oh, Jesus', like that sort of effect, unless it's that, I don't think there's much going on that certainly doesn't last beyond the waking up point, I don't think.

Shashoua, Rebecca 56:58
Yeah.
it sounds like there's a real lag between like acting, doing something or saying something, and then the analysis that follows afterwards, questioning as to why you did that.

Nathan 57:20
Yeah. Yeah. And I think that that doesn't really happen in the dream, I guess because Even with how dream like reality feels to me, I know it's not real, so there's no point wasting what little brain power I've got left on something that's imaginary to a point. I might as well focus on going downstairs and making myself a cup of coffee, because that's where the brain power kind of needs to be for the morning rather than wasting time thinking about something that's like, it's like trying to analyse the emotions from a film. It's, OK, it might have affected you a bit, but it's not real. Cool. OK, you know. See, I think it's allocating the brain Power is subconsciously rather than consciously, but it's just 'it wasn't real. OK', and off we go and you've got something that *is* real, even though it doesn't feel like it. So you just don't really give it too much attention, I don't think.

Shashoua, Rebecca 58:00
Hmm.
And you were saying that brain power that you have at the moment is very spread across lots of different areas.

Nathan 58:23
Hmm, yeah it. It feels like it has to be and it's thoroughly exhausting, I think, and I'm, I'm always, I mean, certainly post-midday, I'm always exhausted all the time because I think even Normal things that most people do subconsciously, like clean their teeth For example, you know, you just do that. You don't even think about it. As for me, it's toothpaste on the brush, right, left, right, left, right. It has to be a very clunky, focused thing Otherwise it just stops. So you have to really focus on every little detail of everything that you're doing And to the point where you just you're absolutely fried by lunchtime. So if I have to make a video for a client with guitar stuff, I know that I need to finish filming by 1:00 o'clock at the latest. I can edit in the afternoon because that's just clicking a mouse and it doesn't really matter if I need to be on a camera playing without making mistakes and knowing what to do and remembering what I've done with the thing I'm demoing and why I haven't yet. And I have to be on. I need a few coffees and I need to do it before lunchtime. After that, it's setting myself up for a fail because I'll just zone out, play more wrong notes than right notes and Do a terrible video and people will moan and so it's not worth it. So yeah, I think I have to really allocate time and brain power and really budget my time and energy. If I've got a long filming day for the big filming project we're doing at the charity, for example, I know that I need an easy day beforehand and I need to put a line through the next two days in my diary to recover from it. I can do it, I can be on for a day and I can drive for four hours and do an interview and drive 4 hours back. I can do that, but I need the circumstances to be right either side of that in order to allow me to do it and need to be very careful with that. And if I try and have a coffee and push through It goes south quite quickly, it's just not good when that happens, you know.

Shashoua, Rebecca 1:00:21
Yeah.
“not good”. In what way?

Nathan 1:00:30
In terms of if I have, three days of filming for example, and I've got to do interviews with people on camera, so I need to be on enough to have a camera in my face and actually conduct an interview and manage it and run it and ask the right questions and all that. On day one, I can do it if I have an easy day beforehand and I can try and sleep well and be refreshed fine by the third interview. I'm just like I can't speak. I can't remember which questions I've asked, which I haven't, and it's just a mess And then I beat myself up over it afterwards, like I

got it wrong.
So I need to make sure that things are right and the thing I've always been so difficult the last few months is that the filming schedule's been crazy. It's just been nuts and I think it was. Where was I? Wolverhampton, Wrexham, Bristol, London, Lisbon, London, Edinburgh. In nine days and it was just like, oh, yeah, and I was ill the whole time. I was just like, oh, shoot me. And so by the end of it, I was just in pieces. I couldn't speak. I was just like, Just get the camera away. I just don't want to be on. It's horrible.
So I need to make sure that everything is kind of very finely balanced in order to get things done to the standard that it either needs to be done to or I want it to be done to. I don't like doing things badly and making mistakes and half arsing things. It's just not something that I enjoy even with the flippancy that comes with depersonalization it's still a bit like, no, I don't- especially if it's something recorded or on camera or you're dealing with someone that you, you have to get it right.
I don't want to leave that to chance and just hope I do enough job and our editor can chop it around enough and make it sound like I can speak. I just want to actually do it properly. So yeah, I think I need to allocate that brain power and the fatigue and all that very carefully, I think.

Shashoua, Rebecca 1:02:19
it sounds like you really have to think about every single action, thought, behaviour. Everything you're doing has a thought process behind it.

Nathan 1:02:34
Yep.
Yeah, and.
Absolutely. And it's 'I've got no food in the house', so I need to go to the supermarket. but If I do that, I also need to do this later and I can't really do both. So what do I do? Do I not have lunch and do the thing I need to do, or do I go shopping and risk that falling to pieces and you're balancing everything like a tray of glasses all the time and the slightest sort of knock and a whole lot falls over, and it all smashes. It's like it's very precarious in terms of getting through life. And the only way I can do it is to make everything as flexible as possible.
If I take on a YouTube video job for a client, I'll tell them I need three weeks. I'm going to aim to do it in five days, but I'm going to tell them so I got that buffer in case I have a rough time. I can not have that extra pressure 'oh I'm a day over, I said I'll have it by yesterday'. I need to kind of make everything very flexible and in terms of the day job I do a couple of days a week for the charity. it's not a couple of days a week. It's whenever I can get an hour in. If I wake up at 2:00 in the morning and there's emails that need doing, and I'm awake and I can do it, I'll do it then because I might not be able to do it at 9:00 o'clock when I'm there with a cup of coffee, I have to kind of just take the hours whenever I can get them and claw them out. So it's very precarious.

Shashoua, Rebecca 1:03:56
Yeah, a real sense of just the unknown of what you will be like, like hour to hour. Almost.

Nathan 1:04:05
Hmm.
Yeah, yeah, exactly. And that's the biggest barrier to being able to- the idea of being able to commit to like a 9 to 5, for example. You know I can generally tell within 5 seconds of waking up in the morning whether it's going to be an OK day or a bad day and some days it's like, nope, I've got a headache. I haven't slept well. I feel like I've still got half a bottle of vodka in me. No, I know. I know what today's going to be. I might get a few emails done, but anything bigger like filming jobs? No.
I'm just not going to be able to do it and you can kind of tell that. So if it's, you have to be in the office by 9:00 o'clock, I can't do it today. So the only work I can do is completely flexible and you'll have to manage certain deadlines. But generally it's there's a few emails need replying to Sometime within the next three days. OK, I can take an hour from there and an hour from here and do it. That's OK. But anything more committed than that is very difficult.

Shashoua, Rebecca 1:05:08
Yeah, yeah.
And so just going back then to what you were saying about your sense of self in your dreams compared to when you're awake?
I know you said your memory for your dreams at the moment isn't very good. Are you able to describe what your dream life is like currently? This was about mid-way through the interview questions and I was aware it had been an hour at this point so I was very much motivated by time here to steer the questions a little

Nathan 1:05:38
Not easily 'cause I I honestly couldn't tell you the last time I had a dream or when that was, or what happened in that dream, or even just knowing that I dreamt something, whatever that was. So I almost never Either have or remember having dreams currently I think. I think maybe the fact I was on those meds during the Dream Diary study kind of skewed the frequency of dreams for me because it was every night I was having like two or three dreams and writing them down. It was so out of the ordinary for me that because it's normally not something I can remember, but I'm not someone that ever really has nightmares really. I remember one that year if that like it's very rare that I have a bad dream to the point of waking up in a cold sweat and very suddenly doesn't often happen. But I couldn't honestly tell you what the themes would be nowadays, because it's just so either not there or not in my memory at all. I'd be making it up if I was to try and come up with a more detailed answer

because I just don't know. You know, I would rather I'd rather give you nothing than give you lies.

Shashoua, Rebecca 1:06:49
Yeah. No, It doesn't matter if you can't describe anything cause that's telling in itself of how everyone's experience is so different with dreams and their memory, so that's teaching us something anyway about your experience

Nathan 1:07:08
OK.
Yep. haha

Shashoua, Rebecca 1:07:12
And so I suppose at the time that you were on the medication and able to - at that time - retrieve like a sense of your true self.

Nathan 1:07:20
Yeah.

Shashoua, Rebecca 1:07:24
have you been able to make sense of that experience around being able to retrieve the true sense of yourself in your dreams? Next question on the interview guide. I felt it was ok to move on to this as he was unable to answer the previous one at all

Nathan 1:07:34
Not so much. I mean, maybe it was just that I was dreaming more and I had more- because I was dreaming more, I was more aware of it, and because I knew I was doing the study. It wasn't the case of wake up at 2:00 in the morning and go and that happened and back to sleep. It was wake up at 2:00 in the morning, get my phone and start writing down exactly what had happened. So it was- I was kind of purposely logging it for the purpose of the study. So I was much better able to remember it because I was writing it down in the moment. Like, I would just wake up and go right quickly, quickly, quickly write it.

Shashoua, Rebecca 1:08:06
Mm hmm.

Nathan 1:08:10
Whereas I don't routinely. But yeah, I think maybe it was…I think part of it was kind of having that realisation that a lot of it stemmed from school and that was a real scenario, even if it wasn't necessarily real events or anything like that. It was based in reality and it was

something that I remember quite acutely going through and being a part of. And it being quite difficult and that it was reality then because it was pre depersonalization. So maybe it was more kind of triggering the memories of what life was like before depersonalization and reflecting back possibly And even though it might not have felt like it, just the premise of what the dream was and the situation and the people and the events and all of it, it was maybe it was kind of pinging back and reminding me of the real memories of the real reality when I had a sense of, sort of more of a sense of self. So it was kind of making that connection because it wasn't fantastical. It was kind of rooted in real, inspired by a true story, as it were. You know, it was, it was, there was some basis in reality And basis in having a sense of self there. And I was just kind of like- it was kind of giving me a bridge to go back there, whereas most dreams, they're not rooted in reality for me, if I can ever remember them so There's less of a sense of self there 'cause it feels so distant, but I was thinking back to a time when I had a sense like That's about the only connection I could possibly make from it, I think.

Shashoua, Rebecca 1:09:55
Yeah. Can you remember at the time - you obviously remembered those dreams at the time of dreaming about school? Can you remember if there was an impact at that time when you woke up about your sense of identity?

Nathan 1:10:10
Mm hmm.
Umm.
I'm not. I mean, possibly I think it was more…It was more that connection with reality and therefore a connection with a sense of self. I think. I'm not sure it talked much about my identity as such, but it was.
I'm have to really think back now. It was a good couple of years ago. I think if it was telling me anything about my identity it was more reinforcing the negative self beliefs Because that was my identity at the time. And you know that's changed through therapy and getting older and just more mature and getting on with life a bit. But at the time the, the identity I had was largely- it was a combination of being very sure of myself in terms of my hobbies and my beliefs and things like that, but My identity in a in a collective was I was very much the bottom rung of the ladder, And I was made to feel that way. And I was constantly reminded that I was the outcast in that whole society.
And maybe it was- Maybe the dreams by taking me back to those points and putting me back in similar situations with the same people, albeit imagined, was maybe giving me a little more of a sense of self, not necessarily a positive one, but it was giving me some it was putting me back in that identity I was in in 2008 and previous, which was the- I don't know what the correct word is I suppose, like the victim in a way or the victim or the butt of all the jokes, how everyone describes it, I was that character with that group of people. And it was a sense of self to a point. It wasn't a positive one and I'm quite glad I got rid of that (mostly)!

But it was, yeah, maybe reminding me of the sense of self I had back then. So maybe it felt more real as a result of- Again, it's that bridge back to as things were. And I had more of a more of a sense of self back then. So in the dream it might have felt Like my current lack of reality, But just the premise of being at that time in that place, there was a sense of self attached to that. So maybe it was like the association between the two. That's about the only connection I can try and make, I think.

Shashoua, Rebecca 1:12:52
Yeah. No that's. Yeah. So it, you talked about that there was a contrast between your identity at that time as an individual versus in a collective and how that, I suppose, yeah. Can. Can. Are you able to describe whether both of those things played out in the dream or A sense of one of them being stronger. I struggled here to know what and how to follow up as seen by my stuttering and self-interruptions. Perhaps partly because we had been speaking for a while, but also I got the sense it was a horrible time for him and he didn't want to speak about it because of how closed he was being in comparison to the very revealing and open answers he had given previously in the interview. Or was he getting tired of the interview? The idea of a collective or individual identity being 'stronger' is a self-imposed idea and didn't follow FANI methods. On reflection, I could have followed up on his statement that he had 'gotten rid of' aspects of his personality. What does that mean? was it intentional? Or being an 'outcast from society'. The word society implies his experience extends beyond school and could also have been expanded on, in-keeping with Bamberg's narrative type sameness vs difference.

Nathan 1:13:17
I I think that the sense of how I was in the in the collective was very Strong in the dream, I think I was very, or the various dreams around that time and ones I can easily remember since. It was the, the sort of 'them and me' Mentality behind it. You know my purpose in that situation as far as everyone else was concerned, was the target mostly. So I think that the sense of who I was in that group of people was very acute.
Thinking back to when it was all really happening, I'm not in the dream. I think I did have that fairly strong sense of self. I think that's maybe less…the self identity as opposed to the collective, I think that was maybe less thinking back in the dreams and maybe that's because I'm so used to that now that that's my current reality is that the lack of self, the estranged self. So maybe that was less like in the dream It was like a very specific Scenario with a group of people, so I wasn't sat there reflecting about, you know, my place in the world and what are my values? It was just a rubbish thing that happened and I woke up. So it was like a snapshot as opposed to anything further reaching or routed so Yeah, I I think that the collective sense of self was much stronger than the internal individual sense of self, I think.

Shashoua, Rebecca 1:14:51
Yeah.

Nathan 1:14:52
Even though at the, in, back in 2008 they were both probably as strong as each other.
In retrospect, through the dream, using that as a bridge, I think the collective sense of not belonging and Being the odd one out, I think that was I think much stronger than Anything internal? Or maybe that's just because it was a snapshot not
Particularly considered it was just, you know, an event that made you feel a certain way as opposed to, you know, a period of reflection in the dream.

Shashoua, Rebecca 1:15:26
Yeah, that part that was stronger, the part, the collective, the odd one out being different mirrors kind of as what how you were describing in the very beginning when you were describing your sense of self and experience of reality now like as an adult

Nathan 1:15:44
I yeah, I think I'm… I think it's probably changed a bit in the last year just because I've been so… having to try and sort of rebuild things up. So it's been a process as opposed to something I've taken for granted or you know you assume you know it but before that…I think… I'm trying to sort of get my head around which part of the sense of self has slipped more than anything else. I think the collective not belonging odd one out thing, I think in in a lot of ways that's still very much there And I've always have felt On the periphery of… not, say society, that sounds a bit grand, but in terms of my friendship group and the people I know in my life, whether they're acquaintances or for family or friends, whatever, I always kind of felt different in some way, and there's very few people that I really sort of click with, I think and feel very close to.
And I definitely fall into the sort of the fixer mentality. So a lot of my purpose in life seems to be or have become defined by what I can *do* for other people. And that's where the worth in them being friends with me or having me around, That's where a lot of that work comes from. Is, that's Nathan what you know, I know what he can do for me to make my life easier. I tend to fall into that fixer mentality.
So I think that's probably an extension of how I felt at school and that's how I just kind of framed it, which is 'nobody liked me So how can I get people to like me if I do stuff for them and I feel appreciated' and all of that, it's probably like a continuation of in terms of a lifelong development of your personality But in terms of my sense of who I am as an individual, I think it's always been quite strong, but it's definitely taken some knocks in recent years and then last year kind of completely blew it apart. But I think I've definitely felt less sure of who I am over the years as it's got stronger and stronger, I felt more estranged from

the character that I act out and I've often described my experience of depersonalization as being I spend my life acting a character, but I *am* the character. So you know, I know how Nathan would react.
What Nathan would say in response to that question, so I will be Nathan. But I'm not. I'm acting it even though I am the character that I'm acting. It is. It's a difficult thing to kind of verbalise, but it's, I know the way I would respond and the inflexions I've put in my voice, I've got my sense of humour, is and I would make an inappropriate joke about most things. So I know that that would be my kind of default response. If someone says something is how can I make that funny? You know? I know that's what I would tend to do So I've just kind of carried on doing that, but I think I've definitely become more questioning of that as time's gone on, especially since last year is am I doing that because that's me or am I doing that just because that's what the metaphorical computer coding says you need to do? 'You hear this, you do this action and you communicate that' is it that binary? I don't know. it's interesting to sort of think about whether the collective or the individual sense of self has slipped more than the other, whether it's just changed and evolved or whether it's gone. I don't really know it's a tricky one. I was never overly bright, but to begin with, but certainly is like capacity's gone down so I have to keep going to Conferences and do talks. The amount of time I just listen to people's talks about depersonalization. It's like I know it's my condition but I've got no idea what you're saying. It doesn't go in at all!

Shashoua, Rebecca 1:19:54
Ha ha ha.
Yeah.
And that the idea of yourself as a 'character' really struck me and I wondered if there was like an evolution of this character that has occurred over the years.

Nathan 1:20:16
Quite possibly, and I think a lot of it's probably just maturity. You know that as an 18 year old, I'm now 34, that's going to change anyone, whether as a character or your personality or who you are, whatever. So I think, yeah, it's probably definitely evolved. I think I've had to… As a depersonalization's got stronger, I've had to become more… not necessarily trusting of who the character is, but blindly accepting it, I suppose, and going well in the early days it would be well, I feel a bit hazy, so I'll just kind of do what I know I do, whereas now it's a bit more 'I can remember what I did 60 years ago so I'll just do that' like I've definitely become more just having to do it as opposed to it being a slight sort of supplement to what's missing is now become like the much greater part of who I am, I think, is that awareness of how you act and having to think about Who you are and what you would say to people, I think that's definitely- I've had to become much more kind of blindly accepting of those ideas than it just… kind of just topping up the last little bit that might have slipped a little bit. It's now the

much bigger part with a little bit of reality kind of underpinning it and popping it up. I think it's kind of top, top down, bottom up, it's going to switch a little bit.

Shashoua, Rebecca 1:21:34
And finally, then, I was just wondering a bit. We've touched on this about the context in which those dreams occurred, the dreams where you felt that you were kind of connected to that former sense of yourself - And I was wondering if there seemed to be times in your life or events where those types of dreams seem to be more frequent or more intense. Or just any patterns you've noticed with what's going on in life and What happens in your dreams? (final interview guide question)

Nathan 1:22:23
not a huge amount I don't think because I think even take something like last year when I was just in pieces for the whole year, I don't remember dreaming particularly Often or in any way really different, and, you know, emotions were heightened and the stress was heightened and everything that you would, or I would kind of assume would trigger bad dreams was kind of going on. if it was going to be kind of prompted, I would guess it would have happened last year and I don't think it really did.
But no, I don't think I've ever really noticed too many. I mean you will occasionally get the…A dream happens and you wonder where it came from, and then you remember something you were reading just before bed. It's like, oh, I can see how that would evolve into what happened. There's been times where I can kind of piece that together, but not often certainly in terms of frequency and the idea of sense of self within the dream and what that, how that might be different, I think the only thing I can really the connection is the…Having dreams about school and I had a sense of self back then. So dreaming about that scenario, it kind of instinctively reminds me of the sense of self and it's almost inherently there without it *really* being there. You just kind of assume you have it more and maybe just because it was rooted in reality to a point it feels more real than everything else, I guess I, but I've never noticed too many patterns in terms of themes and frequency Or anything really, aside from the occasional you read something before bed and it appears, in a overblown way in the dream you can kind of piece the two together. That's about it. I think. I don't think there's been… There's not too much. Again, I'd rather kind of give nothing than make it up and kind of guess and it's not true. I'd rather sort of say I don't really know to be honest

Shashoua, Rebecca 1:24:15
Yeah, and. And the times where you have felt rooted in, in a sense of who you were, they tended to be in that context of being at school.
Like only or were there other?-

Nathan 1:24:32

I think so.
I I think so. Yeah. I think it was probably just that real scenario going back to it.
And it was a it was a real set up, at least, even if I'm inserting a new story into that, it's still a real set up from the past whereas something that's completely dreamt, even if it has, like, you know, a root in something you've read, It's so imagined that It's just my normal daily experience coming out in the dream. So I think possibly dreaming about real life Situations Makes me feel a little more rooted than completely sort of fantastical, Imagined stuff, I think.

Shashoua, Rebecca 1:25:21
Yeah. And you said there was a 'new storyline injected' into that, into that familiar scenario?

Nathan 1:25:30
Into like the school scenario? Yeah. I mean, I don't. There's nothing kind of big and overarching just if I think back to the people I was around and the buildings I was in, it might not be something that actually happened, but it's in line with things that happened and the things being said to me were borderline the same as what was said to me back then. But it might be a sort of a skewing of a real event or something. So it's kind of taking the premise and maybe injecting some Imagination into it as well, but it's rooted. it's like a film that's 'inspired' by real life events. It's not a true story, but it's kind of.

Shashoua, Rebecca 1:26:05
Yeah.

Nathan 1:26:08
You know, there's some basis there, at least, even if the story's Hollywood-ised a little bit, you know, it's kind of a similar idea to that, I think. So because it has some basis in reality, I think I probably feel a little more like it's real and I'm real in that situation because at least part of it actually happened, and it was at a time when I had the sense of self, more so than now, I think. I think that's about the only sort of pattern in terms of sense of self and being rooted that I can really pull out of it.

Shashoua, Rebecca 1:26:43
Yeah. Yeah. No, that's really interesting. Really helpful.

Nathan 1:26:44
Mm hmm.

Shashoua, Rebecca 1:26:48
And I'm aware as well that I've taken up an hour and a half of your time.

Nathan 1:26:50
No, it's like it's absolutely you got me for the long as you need me. It's absolutely fine, Don't worry at all.

Shashoua, Rebecca 1:26:57
Is there anything that I've not asked or anything that you wanted to add to what we've talked about already.

Nathan 1:27:09
Not, not particularly, I don't think.
'Cause I say like I've struggled to remember dreams anyway, so I don't think there's anything that's Particularly standing out as Being worth me sort of raising because a lot of it I don't remember or I'm not aware of or it doesn't happen somewhere between the three. So no I think we've kind of covered like everything. I mean if there's any other questions or anything that's come out that you're interested in, please, by all means ask. Because I'm not hurrying off like I've got really boring emails to this afternoon. So I'd much rather talk to somebody than see it's happening way at a keyboard. So if there's anything else please feel free to ask it.

Shashoua, Rebecca 1:27:47
Yeah, well, I suppose just out of curiosity, how you found the process of recording your dreams because you said it's not something that you normally Remember or think about afterwards. So yeah, how that process was. This was something Helge asked me to gather from participants to help her evaluate the dream diary study.

Nathan 1:28:05
It was interesting because With the medication it was, they [the dreams] were much more frequent, so it kind of made it a lot easier to do the study rather than get to the end of the two weeks and go well. I've had one dream and it was about pizza. I actually had some material to go on. I think the dreams are probably much more vivid in terms of subject matter and whatever it was now, there were various things, but I did notice that trend of school recurring quite often, and I'd never thought about that Before and it probably- it might because they're so tame and watered down and fleeting that I don't even remember them. But certainly with the medication and the fact that I was writing it down at 2:00 AM whenever I had it and making- Actually trying to log it and look at patterns there- It was interesting to kind of make that connection, I think and actually not forget them and go back to sleep, actually write them down and look at two or four how many weeks it was worth the dreams and go 'Oh, hang on. That happened quite often' and it kind of, It's one of those things that it's so difficult being in therapy with this condition because you don't feel like your words are your own. You don't feel like the therapist is a real person and their words are real. And because pretty much the

only therapies that exist for this is talking therapies, It is literally like going to therapy drunk. You know, you go to the session and you just one of my friends says you make the right noises.
You leave and you what has happened? You never internalise that all CBT is looking at patterns and internalising words and analysing stuff and making changes and positive affirmations all that sort of stuff. It's like being drunk about the whole process. It just doesn't really work.

Shashoua, Rebecca 1:30:01
Yeah.

Nathan 1:30:03
And it was interesting, kind of Actually, looking at the dreams 'cause, it gave me a bit of a window into what might be going on and coming out when you prompt it.
and It is a little bit like… I always sort of say about alcohol to people. So I think alcohol is quite a good level. It shows you who someone really is. A lot of the time it obviously gets to a point where you goes over a bit of a cliff, but you know you give someone a few drinks and you tend to see who they probably really are underneath. I might be talking complete rubbish, but that's always my perception. You get someone that's very quiet and they Drink and they become really angry. It's like they're probably quite an angry person, but they're just... They bury it and it comes out And when you get rid of the defences and that's what comes out. And I think whenever I drink, what tends to…. I'm very sentimental. I think that comes out. I'm always quite sort of soppy towards people. Whenever I drink, I think that's probably indicative of who I am Deep down, I just try to kind of shield it a little bit. And I think that's kind of what the medication and logging the dreams did for what might be driving or at least as a starting point for what I need to look at in therapy, which was this theme is recurring. and I'd never thought of it, and it's probably just because on the meds that it was coming up as often as it did and I was deliberately trying to remember it, but it's like I'm dreaming about school all the time. Why? I'm not dreaming about other things from life. But the thing that the therapists have kind of gone well, you know, 'that could have really shaped who you are'. 'That sounds really difficult'. And 'wow, that happened. That's terrible'. Well, it doesn't feel like it. I know it is subjectively, yeah, but I wasn't really. It doesn't feel like my memory, it's still coming up over and over again.

Shashoua, Rebecca 1:31:53
Yeah. So you were having therapy at the time, speaking about school?

Nathan 1:31:54
Was it during COVID that with the dream stuff? Yeah. What? I think I just finished my last course of therapy. I think it was in the middle of 2019, I think, was when I finished it. So no,

I wouldn't have been in therapy at the time. But I'd had lots of therapy where people tell you that things that have happened to you in your life are terrible. It's like, well, it doesn't feel like it. I feel completely estranged for it. And yet that's still recurring in dreams. Like, I guess it's a little bit like I was saying about last year, I was crying. I don't know why, because I kind of knew what I was probably feeling, but the reaction was so out of the blue. But maybe that was just indicative of how much it was affecting me, even though it I knew it was, but it still felt quite surface level at that point But it was obviously something deeper happening and it was coming out and that was indicative of- i've kind of taken the dreams as more of a cue as to what's maybe *actually* going on in the same way as I did it about, like, crying last year and All the other sort of like using the using it as a cue to kind of trying take an educated guess as to what's worth looking at and what's probably happening even if I don't feel aware of it or feel estranged from it or it's not a big deal when People say it is. I'm kind of using it as evidence, I think.

Shashoua, Rebecca 1:33:22
Yeah, yeah. And you said- something you said struck me. You said that there's a sentimental part of you, but you kind of shield that. Though I initially considered the interview to have ended I then thought this would be useful content for the analysis too

Nathan 1:33:33
Hmm I think…And this is largely for me pulling my personality apart a little bit from therapy informing it. I think a big part of that is I kind of grew up in a household,
And went to a school - So I think the two together - Where if you Kind of expressed an emotion that was instant ammunition to pound you into the ground like a tent peg. So you just didn't express it. If something upset you know 'what's wrong with you?', 'I'm fine'. There's plenty wrong with me But you just, you know, you're very stoic about it, and I think that's for a long time, That's kind of how I was in *all* of life, was just know if I felt happy about something. You don't express it if you felt sad about something. You don't express it. You just keep it very sort of poker faced all time And I think you know when, therefore I started having drinks and I was like 18 or something, That's what started to come out And I think that it's probably… I've got one parent in particular who was very like that or still is, you know, gets worse every day and another parent who's quite caring and outgoing and sentimental, But I think because of the environment it was, you kind of shielded yourself from the nasty one and kept it very closed off and certainly at school, you know, if you're upset about something and you let it show, Straight away, you know, you were just toast. So you learned to kind of bottle it up and grimace through it and get home. And as soon as you got home into your bedroom. When you're on your own, you just cracked. And I was in tears. You just bottled it up so much. And I think that was kind of how I've always been a lot of the time. So I think I'm a lot better with it now Overall, but certainly when I when I drink, it tends to be that that comes out. That I just kind of tell people how much they mean to me and

things rather than get punchy. You know, that seems to be the side of my personality that comes out once I take those defences away. That's what's there because I think it's always been there. I've just had to bury it and to be very closed off as a protective mechanism. And now that I'm, you know, 34 and I've kind of peeled that away to a point And you throw a few drinks and they're kind of properly get rid of the scaffolding, That's what's there is just kind of having to sort of tell people what they mean to you. And I think that's always been like that just never been allowed to be like that, I think.

Shashoua, Rebecca 1:36:10
yeah, it sounds like you've had a lot of realisations about those types of things through the therapy you've had and Also, before, when you were saying about not remembering things from therapy, I was just curious because of the way that we're doing this interview now and that it's being recorded, whether you've ever recorded your therapy sessions or – it was just a thought, like a side thought I had away from this interview about whether you've ever been able to do that

Nathan 1:36:48
You know only once and it was when I was going through the maudesley back in 2018-19 and one of the things they actually encouraged was recording your therapy sessions. So what I used to do was, because I live in Bristol and I had to get to London every week and I had no money, So every week was on the Mega bus for like 7 hours a day, What I would do is I would get the bus to London early and I would walk from Victoria Coach station down to the Maudsley, which is about an hour and the therapy sessions were an hour, so I'd always put my headphones in and listen to last week's therapy session on the walk down to the current one so that it was more fresh in my brain and i tried to have... So I think otherwise I end up repeating myself which I probably have done a lot today like I just kind of autopilot it and kind of don't think about what I said earlier.
And yeah, so I tried to kind of have it at the front of my mind, so I was less repetitive or if I was asked about something from last week, I could actually go. 'Oh yes, that' and actually have it more at the front of my mind. So yeah, I did do that then.
Aside from that, not so much. But then the other therapies I've had haven't been particularly targeted, certainly not for depersonalization. It's more been sort of general I apps CBT. We'll give you this in the meantime to keep you quiet type stuff rather than having any awareness of the problem or the condition or anything. It's more just you know to try this medication and see how you feel type stuff. So it's been much more sort of surface level I think.

Shashoua, Rebecca 1:38:26
Yeah. Yeah. well, thank you. For, sharing that insight around your therapy experiences of in researching this, I've read a lot about how because it is so.

Nathan 1:38:29
Hmm.
No worries, no.

Shashoua, Rebecca 1:38:41
Newly researched and not a lot has known about it that therapy is really difficult. Access to therapy and therapists who have an understanding of the condition. So I'm really hoping through contributing to research about it and giving like first hand experiences of what it's like that there can be some implications for, you know, clinicians having a better understanding of what its like to have dpdr

Nathan 1:39:04
Absolutely. I think it it's it's a condition that's been known about or at least spoken about since like the eight late 1800s. It's not a new thing, but it's been so neglected by academia and research and healthcare that I think I mean you've probably read the stat as well the prevalence in terms of chronic 24/7 clinically significant depersonalization, It's the same as that OCD and schizophrenia. Everyone's heard of that there's NHS services and protocols to treat that or to help with that.
And yet the prevalence is the same for this, and still, you know, I've had psychiatrists Google it in front of me when I've gone in with the name. 'Oh, this is fascinating, isn't it?' And then they're Googling it. So it's. It's the training. Just isn't there? The vocabulary to describe isn't either or people choose not to try and describe it for fear they might be thought of going crazy and sort of just. I'm nicking a quote from my friend [name redacted]. She's an assistant professor at Birmingham University. She has the 'two halves of silence' Quote the training isn't there, but the vocabulary and willingness to use a vocabulary isn't there either, so you just have this gulf in the middle, where there's just a huge lack of awareness. No one can really speak to each other, so hopefully, as you say that the more studies that happen, the more people look into it, The more celebrities you have talking about their experiences with it online, the Internet's helped hugely in all of that. And you know, there's one specialist tertiary care service, Hopefully there might be more at some point, no idea, but this time. But it's a it's a such a huge problem just.

Shashoua, Rebecca 1:40:20
Hmm.
Yeah, yeah.

Nathan 1:40:40
Even if you do get to see someone who's a DP 'expert', they know the textbook theory. But in terms of the real world implications, it's so surface level they know more than most, so it's

great to see those people But equally I remember, have you ever come across- If you've read lots of papers, you might come across Doctor Anna ciaunica? She's like, yeah, she's a philosopher. She's the one I was doing a talk before down in Lisbon the other week. And and she sort of said that a lot of I think she's done studies on this.

Shashoua, Rebecca 1:41:02
Yeah.

Nathan 1:41:11
There was a big rise in DP levels during COVID and part of it might be because it was such a weird time to live through, When you're less socially connected. But also it was it was linked to use of digital technology like zoom and teams, and her theory is you're looking at yourself on the screen all the time. We're not designed to look at ourselves. You know, we're designed to look at other people and looking at yourself is weird and it triggers all those sorts of things. And I heard a story a while-. I think it's probably a lot of truth in that-. I heard the story of like, a DP therapist Told someone to go home and stare at themselves in the mirror for hours and in until they felt more real! It's like, well, something doesn't add up here like that Sounds very counterintuitive at best, like and that's the sort of thing like, 'I feel estranged for myself in the mirror'. 'Well, keep looking and see if it changes'. No! that's totally wrong! You know, they might know the theory, but equally, like, there's a much bigger iceberg that unless you've lived with it and been through it, a lot of people just it's really difficult to get.

Shashoua, Rebecca 1:41:47
Oh.
Yeah.

Nathan 1:42:13
And that's one of the battles we find that the charity is trying to get people to actually understand it. And the only way I've really been found to actually do that successfully is try and find times in people's life where they might have experienced it 'normally' and transiently. Like, you know, if someone dies suddenly and they get the phone call to say, someone close to you has died or you're in a car accident, another good one, you'll often hear both those things. Like, 'I felt completely numb'. 'It felt like a bad dream'. 'It felt like it wasn't really happening'. Take that and extend it over a lifetime. Like try and find those ways in the book and actually relate to what it might be like Because the amount of times I've said it feels like I'm drunk all the time, 'that sounds brilliant!'. Please don't say that, It's so frustrating.
But yeah, it's it's so hard to actually have a therapist that gets it. They might understand more, but they don't *get* it. And it's difficult to.

Shashoua, Rebecca 1:42:53
Yeah.
Yeah. Understand it on like an intellectual level, but not really put their self in your shoes.

Nathan 1:43:06
Exactly.
Exactly. Exactly. Yeah. It's very difficult when they're the ones that are best qualified to help you But equally you end up- I mean, I remember at the Maudsley, I remember travelling on the bloody Megabus for like 7 hours that day and having a 20 minute conversation about herbal tea and which tea would be best to help you with that. I can figure this out myself down Tesco, can we actually get to the therapy, please? Like it's just I don't want to talk about bloody tea!

Shashoua, Rebecca 1:43:35
Yeah!

Nathan 1:43:36
It's. I don't even like caramel go away!
So yeah, It's a big struggle with therapy in general, but people are starting to look at that now in terms of interventions taking existing therapies, but modifying them to be more successful for dissociation and whether that's delivering the therapy while you're out for a walk to distract senses and all that sort of stuff, people are starting to think about how to adapt the interventions to be more suited to the problem.

Shashoua, Rebecca 1:44:01
Hmm.
Yeah.

Nathan 1:44:07
Because talking therapy for a condition where you feel like words aren't real just doesn't work for me. How's that ever going to really help when it's chronic? For decades. I mean, if someone has it transiently or it comes and goes a bit, you can look at the patterns. You can manipulate patterns. All of that. That's fine. But when it's like 16 years of solid DP. How are you going to fix that with words? Really, if words don't go in, it just doesn't really line up. So the fact people are starting to think outside the box and develop intervention specifically for the dissociative conditions now. And with Depersonalisation as a focus of that, it's this really nice to see, but I think it's going to be a slow journey, but it is starting to move a little bit I think.

Shashoua, Rebecca 1:44:47
Yeah, that's really interesting. That idea of like being out in nature or doing other things to distract you whilst speaking about things.

Nathan 1:45:02
I mean, I guess it's a similar type principle to things like EMDR. You know, where you're distracting the senses to. I mean, I I don't know anything about brain science, but it's to stop the amygdala alarm system going off by distracting that sort of thing. I guess it's a similar type concept of delivering therapy when the senses are distracted, especially if it's trauma based, to stop you closing down because there's senses are distracted by, you know, air and trees and birds and all that.
Or just walking, getting a heart rate up, whatever it might be increases your interoception or whatever it is. It's all those sort of things. People are starting to think that maybe words alone aren't enough, which I in my experience at least, would agree with, I think.

Shashoua, Rebecca 1:45:45
Yeah. Is that something that you've come across like at conferences or any papers or anything I can include it in the recommendations?

Nathan 1:45:53
Hmm. Not yet. It's more anecdotally from people I've spoken to one-on-one and I know people are starting to plan studies now. I mean, hopefully in five years time, there might be some papers on it, but it's that people are starting to think about that now and you know, how can we adapt therapies to be more effective and things like that so that there's the CBT model that I'm guessing you've come across. Doctor Elaine Hunter?

Shashoua, Rebecca 1:46:08
I haven't no.

Nathan 1:46:25
Was the clinical lead of the Mauudsley DP service for 20 years or something. She she's now kind of in private practise and doing a bit of work with UCL rather than Kcl, but she's kind of developed the CBT model for depersonalization. There's a feasibility study that I'm part of the trial management group for that's ending soon Actually, it's now in sort of analysis stage, Of whether like it's feasible to train existing CBT practitioners on the NHS to deliver this specialist model of CBT. So that's very baby steps. It's like 2 boroughs in London was part of the study. So you end up with like a sample size of 20 or something tiny but that sort of thing starting to be done whether it can actually even if it's just raising awareness of it because so

many times you know I think the average diagnosis period is like 7 to 12 years or something for the condition.

Shashoua, Rebecca 1:47:01
Hmm.
Yeah.
Hmm.

Nathan 1:47:23
It just getting that down alone. You know, early intervention identifying and treating it early rather than letting it get ingrained for a decade has to be a good thing. So even if it's just that, that's good. And yeah, I know certain people are starting to talk about, like, the adapting the therapy type idea and how can we take existing therapies and make them more impactful for someone that feels like they're not real? How do you do that?

Shashoua, Rebecca 1:47:46
Yeah.

Nathan 1:47:49
And I mean, this is just me ranting in the personal capacity here- I really hope we can start to see some more medication trials.
Because that was when the Maudsley first started back in the 90s, It was a research unit before it was a treatment centre and a lot of it was medications and it and it was a quite, you know, take this and see how you feel. We've got no idea what the science is, but what's worse is going to happen type, you know, a bit, gung ho with it. But there aren't really any medication trials anymore. And I think that's one thing that I don't like medications. I hate being on medications, but they don't rely on cognition to have an effect if they're going to have an effect. You don't have to have to think your way into the it working. It just kind of, you know, it's like taking paracetamol for a headache. It just works. It's gone.
You know it, it has more of a... So I don't like it. I don't think there's a magic pill or anything like that, but I hope people start to kind of at least enhancing the therapy and making it more effective by reducing the levels of dissociation a little bit. So the therapy is more effective, whatever it is supplementing the therapy. I hope people will start to look at that more a little bit because I think whilst you know it's idealistic to think it could ever cure it, it might… It doesn't rely on the cognition. So maybe there could be something

Shashoua, Rebecca 1:48:35
Hmm.
Hmm.

Nathan 1:49:06
But everything is off Licence for depersonalization. You just can't access anything and even the limited studies that have been done, you can't get anything beyond SSRIs and SNRIs because it's off licence and GPs and psychiatrists can't prescribe it freely, which is which is a good thing. A lot of the time, but equally frustrating when you know there's a limited study about stimulants and how some people got affect from it but you can't get the things because it's off licence. It's so annoying when you've tried everything else. You know, just give it a go but.

Shashoua, Rebecca 1:49:19
Yeah.
Yeah.
Yeah, yeah, it's fascinating.

Nathan 1:49:36
So I hope it comes back a little bit in terms of that but.
Even in like this, the study sense, like on the charity website currently, I think there's seven active studies recruiting for people. That's never happened before and like the the conference just in Lisbon I did with Anna Ciaunica, I did a bit last year as well and it was in this massive, quite intimidating venue and the conference had depersonalization in the name of it, the sort of international academics conference. And it was about depersonalisation. That's never happened before, that wouldn't have happened five years ago. So things are Starting to slowly move in the right direction and people are starting to take an interest in it.

Shashoua, Rebecca 1:50:16
Yeah.
Yeah. And it sounds like your documentary's really contributing to that as well getting things out there, yeah.

Nathan 1:50:20
Baby steps.
Hopefully we'll do. Hopefully we'll do. Yeah. It's going to be a much longer term project than we were hoping for, but we initially started thinking like a sort of BBC style talking heads documentary, very factual.
And we were talking to various production people about working with them or getting it picked up. But it quickly became obvious that we, the first thing we were going to do was lose creative control because they would want to do it with their presenters. Someone started talking about getting Stacey Dooley and like, no, no, no.
Please don't. So it's like we need to tell this story as it needs to be told. So we're now doing it

as a kind of docu film. So we're going to try and get into film festivals and things and if you can get into a Film Festival a gets seen by a lot of people, but also all the Netflix type people are there and you might be able to sell it as a product rather than get them involved on the front end. So we're doing like a shoestring budget, but fortunately one of our board members as a filmmaker and I'm happy to stand in front of a camera.
And one of the good things that came out of the production talks was this production lady was saying, like you do you, what you need is a film crew and a famous presenter. That's all you really need for a thing. And we did this teaser and he was using his like 4K Netflix approved camera and I was doing the presenting and she actually sort of watched. I went you've got this. You're the ones to do this. Go and do it and like you can make it look pro. You can do it. Let's go. So that's just like OK we will. So that's kind of what we're doing now but in a sort of filmic way. So it's more of a sort of road trip of you know like cameras in the car like Top Gear. I was driving along and talking about who we're going to interview and.

Shashoua, Rebecca 1:51:54
Yeah.

Nathan 1:52:01
All sorts of stuff, so it's more like a journey meeting people as opposed to a factual sort of panorama type thing.

Shashoua, Rebecca 1:52:02
Yeah.
Oh, wow. I'll. I'll keep my eye out on your website. I seem that's maybe where the charity website where you might post in future when it's.

Nathan 1:52:08
Hopefully.
It all, I mean it's it's not likely to be pieceed together, I mean probably later this year and then if we get it into film festivals or whatever, but whenever there is some news on it, it will be on socials and website and stuff like that. So we'll we'll be shouting about it as and when it happens, but it's it's a bit of a headache for our producer because he it's kind of the opposite. He's a filmmaker, so he's used to scripting and filming this is you interview everyone. You've got no idea what they're going to say. And then you have to go through 50 hours of footage to try and find the story that links it all together. So he's just trawling through it and pulling his hair out at the moment.

Shashoua, Rebecca 1:52:33
Yeah.
Oh gosh, what a job.

Nathan 1:52:53
Yeah, yeah, I don't. I don't envy him that.

Shashoua, Rebecca 1:52:56
No.

Nathan 1:52:57
But yeah, so it's it should be good once it's out and if it does get in the film festivals, and especially if it wins awards or anything that it would be like the the biggest awareness raising the conditions ever seen hopefully. So it'd be really good as and when it happens, but it'd be a long, long term project I think.

Shashoua, Rebecca 1:52:58
Oh.
Yeah.
Yeah.
Yeah. Fascinating. Nathan, thank you so much for your time.

Nathan 1:53:16
Hopefully.
No problem at all and and as you go through the rest of the the study and PhD or whatever, anything that comes to mind, just shout like on my I'm generally sat at my desk and much rather talk to people and do emails and website work. So I'm if anything you need to like you've got any questions or you want to chat again just shout. I'm more I'm always around so I'll happily jump on another call.

Shashoua, Rebecca 1:53:31
Yeah.
Thank you. Thank you so much. I hope you enjoy the rest of of your week. We've just got started with the week, but yeah, enjoy the rest of your week.

Nathan 1:53:40
No worries at all.
Yeah.
Already waiting for the weekend.

Shashoua, Rebecca 1:53:51
Me too.

Nathan 1:53:52
Yeah.

Shashoua, Rebecca 1:53:53
And just on on payment as well, we're sorting out funding and I'll be back in touch.
To to get your bank details to send that over.

Nathan 1:54:02
No, no, no worries on that front at all. Don't worry too much. That's absolutely fine. But cool, cool, excellent. Lovely to chat and hope to chat to you soon.

Shashoua, Rebecca 1:54:08
Great. Thank you.
Thank you. Take care. Bye.

Nathan 1:54:12
See you later. Bye bye.

Shashoua, Rebecca stopped transcription