“A stranger in a strange world”: A quantitative and qualitative account unravelling depersonalisation and derealisation, the diagnostic journey and future recommendations

Sarah Dunstan

A thesis submitted for the degree of Doctorate in Clinical Psychology (DClinPsych)

School of Health and Social Care

University of Essex

July 2025

Acknowledgements

I would like to thank the following people for their support in helping me complete this thesis:

First and foremost, I would like to express my deepest gratitude to my supervisors Dr Helge Gillmeister and Dr Antonella Trotta who have been instrumental in helping bring this thesis together. Thank you for all the time that you spent meeting with me and the hours you spent offering thoughtful and detailed feedback which guided me in my role as a researcher. Thank you for sharing all your expertise and taking the time to answer any question with patience and at any time of the day or night. I am grateful that you have stood alongside me sharing the mental load and kept me going during the more difficult times in the project.

Many thanks go to the people who kindly gave up their time to participate in this study. In particular, I would like to thank the 10 people with DPDR who participated in the interviews and spoke candidly about what it is like to live with DPDR. I hope that this study has captured your experiences in some way and contributes to an ongoing understanding of DPDR that helps to improve future diagnosis and treatment.

Thanks to all my friends who have offered kind words of support and encouragement throughout the process of writing my thesis over the last three years and who have been so understanding when I have not been available to join a social occasion or have a catch-up.

Thanks also to my placement supervisor Dr Naomi Sams, who has stood by me and picked me up when my energy was at its lowest. Thank you for all your texts reminding me to keep going and reassurance that I was doing a good job. Additionally, thank you for your patience and for giving me the time and space that I needed to complete the project. Your support really has been invaluable.

Finally, thank you to all my family who have offered advice and support throughout this process. A big thanks to my parents who have stayed calm and supportive throughout this stressful period and have continued to offer words of encouragement. A thanks also to my auntie who has given great advice and supported me throughout the whole doctorate. I have always appreciated all of you.

Abstract

Depersonalisation derealisation disorder (DPDR) is a dissociative disorder typified by a sense of disconnection from one's body and environment. Emerging research suggests that self-concept clarity may play a role in DPDR, potentially reflecting disruptions to self-development following adverse childhood experiences. However, both the aetiology of DPDR and qualitative accounts of the disorder remain underexplored. This mixed-methods study, comprising of one quantitative and one qualitative study, aimed to explore the lived experience of DPDR with a particular focus on the relationship between familial and non-familial adverse childhood experiences and depersonalisation/derealisation experiences and the role of self-concept clarity in the relationship. Religion and gender were also considered given their potential influence on trauma processing and identity development.

In the quantitative phase, participants completed an online survey comprising measures of childhood trauma (Childhood Trauma Questionnaire Short Form), depersonalisation/derealisation (Cambridge Depersonalisation Scale; Felt Sense of Anomaly Scale), depression (Patient Health Questionnaire-8), anxiety (Generalised Anxiety Disorder-7) and self-concept clarity (Self Concept Clarity Scale). Significant correlations were observed between DPDR symptoms and multiple forms of childhood maltreatment, including familial and non-familial emotional abuse, emotional neglect, and physical neglect... Regression analyses found that these maltreatment types significantly predicted greater depersonalisation/derealisation, with no additional predictive value from gender or religion/spirituality. A mediation analysis suggested that self-concept clarity partially accounted for the association between DPDR symptoms and childhood emotional abuse, emotional neglect and physical neglect.

The qualitative phase involved 10 semi-structured interviews with participants recruited from the quantitative survey who self-identified as having a DPDR diagnosis. Thematic analysis identified six themes with nine sub-themes, illustrating the profound sense of detachment associated with DPDR, its overlap with anxiety and depression, and the impact of limited professional knowledge.

Overall, the study advances understanding of developmental mechanisms underlying DPDR and the possible mediating role of self-concept clarity. Moreover, frequent misattribution of DPDR symptoms and limited professional awareness contributes to challenging healthcare experiences and feelings of hopelessness which may exacerbate symptoms. Consequently, increased professional education, clearer diagnostic criteria, and improved treatment guidelines are recommended to reduce distress for individuals with DPDR.

Keywords: Dissociation, Depersonalisation Derealisation disorder (DPDR), adverse childhood experiences, abuse, self-concept clarity (SCC)

Table of Contents

Chapter 1

Chapter Overview

Chapter 1 introduces the concepts of dissociation, depersonalisation and derealisation. It defines depersonalisation derealisation disorder (DPDR) and presents existing research which already contributes to the understanding of DPDR. The existing research highlights DPDR's diagnostic characteristics, potential causal mechanisms, mediating factors in its expression and theoretical models. This section finishes by outlining the research questions for the study and an overview of the thesis. This is followed by a systematic review exploring the relationship between interpersonal abuse and DPDR.

Introduction

Dissociative experiences have been observed since the late 1700's (Tracy, 2022), leading to scientific and medical research investigating the experience of dissociation thoroughly in the late 20th century (Kihlstrom, 2001). As a result of this research and recognition of dissociative experiences, they were introduced in the first edition of the Diagnostic Statistical Manual of Mental Disorders (DSM), although this was under the term 'psychoneurotic disorders' (Kihlstrom, 2001). The term 'dissociative disorders' was only established in the third edition of the DSM (Kihlstrom, 2001). The DSM-5 subsequently recognised five different types of dissociative disorders, one of which is depersonalisation derealisation disorder (DPDR; American Psychological Association; APA, 2013). DPDR is a mental health condition which creates a feeling of being disconnected from the body, physical and emotional feelings and the environment (Wilkoo et al., 2024). The DSM-5 (American Psychiatric Association [APA], 2013) and the eleventh edition of the International Classification of Diseases (ICD-11; World Health Organization [WHO], 2022) classes DPDR as a dissociative disorder. Depersonalisation is described as an out of body experience, where the person witnesses their thoughts feelings and actions from afar whilst derealisation is a perception of the world being unreal (National Health Service [NHS], 2023). Symptoms of DPDR include a feeling of detachment from the body, physical and emotional numbing, distortions in the perception of time and a lack of emotional connection to personal memories of past events (APA, 2013). Episodes of derealisation are typified by auditory and visual experiences which cause distortions to reality (APA, 2013). To receive a diagnosis of DPDR, the DSM-5 highlights that a person must experience ongoing or repeated experiences of depersonalisation, derealisation individually or together (APA, 2013).

Most adults will experience one episode of depersonalisation or derealisation in their lifetime (Murphy, 2023), but this does not necessarily lead to DPDR. Situations that can trigger feelings of depersonalisation and derealisation include traumatic events such as abuse and substance use (Wilkhoo et al., 2024). DPDR can be difficult to identify due to the subjectiveness of the experience. The typical age of onset is age 16 and less than 5% of people experience the onset of symptoms after the age of 25 (APA, 2013). DPDR regularly fails to be present in training manuals for healthcare professionals (Eley 2017,) adding to difficulties with identifying and diagnosing DPDR.

History of depersonalisation and derealisation

The history of depersonalisation and derealisation is complex. Some of the first recounted stories of depersonalisation experiences was shared by an otolaryngologist called Maurice Krishaber in 1873, who labelled these experiences "cerebro-cardial neuropathy" (Sierra & Berrios, 1997). The term depersonalisation was then first used in 1898 by Ludovic Dugas (Sierra & Berrios, 1997). Dugas was investigating the experience of "false memories" and discovered the experience of depersonalisation (Sierra & Berrios, 1997). He read a description of the experience of depersonalisation in Henry Amiel's (Swiss philosopher) personal diary and believed that Amiel was depicting his psychological experience in words (Sierra & Berrios, 1997). This description helped Dugas to define the term depersonalisation and provided a label to help understand strange sensations and feelings that are experienced outside of the self (Sierra & Berrios, 1997).

Depersonalisation and derealisation were not seen as two separate entities until 55 years later by physicians Mapother and Mayer-Gross (Bezzubova, 2014). Despite this, the overall term depersonalisation remained in research and clinical practice, with derealisation being seen as a feature of this experience rather than something separate (Bezzubova, 2014). This pattern followed in the DSM, the first edition of which, published in the 1950s, did not see depersonalisation and derealisation as distinct experiences from each other and were believed to occur at the same time (Kihlstrom, 2001). Thus, they were described under the term 'depersonalisation' and included within the grouping of dissociative disorders, termed 'psychoneurotic disorders' (Kihlstrom, 2001). In the third edition of the DSM published in the 1980s the term 'psychoneurotic disorders' was changed to 'dissociative disorders', yet the idea of depersonalisation and derealisation being the same experience persisted (Kihlstrom, 2001). Depersonalisation and derealisation were eventually acknowledged as distinct features and subsequently recognised as DPDR in the DSM-5 published in 2013 (Bezzubova, 2014). Although it took a while for depersonalisation and derealisation to be recognised as two separate features in the DSM 5, this was recognised earlier in the ICD-10 (WHO, 1992). Yet, it took until the ICD-11 (WHO, 2022) for the diagnosis to be re-classified as a disorder instead of a syndrome and moved to the group of dissociative disorders rather than the neurotic disorders (Reed et al., 2019). Therefore, the diagnosis of DPDR has changed over the years with the two main diagnosis manuals differing in their understanding of the disorder causing further confusion.

Diagnostic Characteristics

In addition to the manuals differing over their criteria for a DPDR diagnosis, the term depersonalisation was vague and explained multiple experiences from a slight detachment from reality to a full out of body experience (Spiegel & Cardeña, 1991). Given this lack of a specific definition, it seemed that many people were experiencing depersonalisation in various situations. This was supported by Hunter et al. (2004) who found that depersonalisation and derealisation can affect up to 74% of the general population at some point in their lifetime, suggesting that this is a common experience. Furthermore, approximately 31% to 66% of people that are exposed to a traumatic event are likely to experience depersonalisation and derealisation (Hunter et al., 2004). Despite these high prevalence rates, depersonalisation only became clinically significant in approximately 2% of the general population due to the chronicity and severity of the symptoms (Hunter et al., 2004). However, other research suggested that prevalence rates of depersonalisation and derealisation differed greatly (Lee et al., 2012), possibly as a result of the confusion about this experience. This makes it difficult to understand the causes of depersonalisation and derealisation and why it occurs in some individuals and not others.

The DSM-5 (APA, 2013) diagnostic criteria itself is also limited in helping to detect and diagnose DPDR. It asserts that a diagnosis of DPDR can only be provided when "the disturbance is not better explained by another mental disorder" (APA, 2013, p.302). This results in a narrow focus on what constitutes DPDR and fails to recognise experiences of depersonalisation and derealisation which occur in the context of other disorders such as PTSD. This is problematic because it has been found that it is common for depersonalisation and derealisation to co-occur alongside other mental health difficulties. For example, 60% of individuals with a depression diagnosis were likely to experience depersonalisation and derealisation in a study by Hunter et al. (2004). This increased to a prevalence rate of up to 82.6% for those with panic disorder (Hunter et al., 2004). Furthermore, the transdiagnostic status of depersonalisation and derealisation is complex and it is difficult to differentiate DPDR from other mental health conditions which produce similar experiences. Additionally, feelings of depersonalisation and derealisation are present in numerous mental health disorders (Tomalski & Pietkiewicz, 2022). In the DSM-5, the diagnostic criteria for DPDR lists seven differential diagnoses including major depressive disorder, obsessive-compulsive disorder, anxiety disorders and psychotic disorders (APA, 2013). A study by Humpston et al. (2020) found that feelings of depersonalisation and derealisation were one of the first symptoms present in people with a diagnosis of schizophrenia, particularly schizophrenia-spectrum psychoses. Moreover, research into depersonalisation has evidenced that people with experiences of depersonalisation are likely to also meet the diagnostic criteria for depression and anxiety (APA, 2013). In addition to difficulties with distinguishing DPDR from other mental health conditions, the DSM-5 adopts a categorical-disease model rather than a symptom-driven model. This means that the subjective lived experience of people with DPDR is not always captured by the criterion and can lead to people with the condition not receiving an appropriate diagnosis. The DSM-5 criterion for DPDR emphasises that depersonalisation and derealisation experiences have to be markedly severe in order to receive a diagnosis of DPDR (Tomalski & Pietkiewicz, 2022), but this is not always the subjective experience for people with the condition. Other limitations of the DSM-5 diagnostic criteria include its poor guidance on how to treat DPDR and its simplistic model of DPDR which fails to fully recognise the complexities of the condition. Consequently, these issues with the main diagnostic criteria for DPDR make it extremely challenging for people to receive a standalone diagnosis of DPDR. This research therefore hopes to contribute to the understanding of DPDR in the hope that it will help future diagnostic criteria to be led by a symptom-driven model which recognises the transdiagnostic nature of DPDR and views the phenomenon along a continuum.

Another reason for depersonalisation disorder’s inadequate recognition is a lack of research studies in this area (Baker et al.,2003). This absence of research and missing interventions led to the foundation of the Depersonalisation Research Unit in 1998 (The British Psychological Society, 2000). The Depersonalisation Research Unit investigated depersonalisation further and distributed literature and findings from research studies in this area (Senior et al., 2001). This literature indicated that depersonalisation often presented alongside anxiety and depression (Cassano et al., 1989; Lambert, Senior, Fewtrell, et al., 2001). This was reinforced by Hunter et al. (2004) who discovered that higher rates of clinically significant depersonalisation and derealisation have been associated with populations that have experienced Post-traumatic Stress Disorder (PTSD), have a diagnosis of depression or a diagnosis of panic disorder. Furthermore, it was unclear whether anxiety and depression was secondary to depersonalisation or if depersonalisation was secondary to anxiety and depression (Hunter et al., 2004). Moreover, the Dissociative Experiences Scale (DES) specifically designed to assess experiences of dissociation such as depersonalisation and derealisation, could not differentiate between a primary or secondary presentation of depersonalisation (Lambert, Senior, Fewtrell, et al., 2001; Senior et al., 2001). This suggested that the DES was not a valid psychometric measure to diagnose depersonalisation. These findings indicated that depersonalisation was a complex phenomenon that needed further clarification and exploration, in addition to a valid and reliable psychometric measure. Despite this early research, DPDR is still considered to be underresearched and understudied (Michal et al., 2016; Wilkhoo et al., 2024), indicating that more research is required to support clinicians with making accurate diagnoses of DPDR.

Potential causal mechanisms

It was initially assumed that sensory disruptions led to the experience of depersonalisation and derealisation and it was later described as “the loss of a brain mechanism that causes the feeling of mental experiences and their attribution to the self” (Senior et al., 2001, p.128). Depersonalisation and derealisation experiences are now understood to be caused by a combination of environmental, social, psychological and genetic factors (Schäfer, 2025). For example, a literature review exploring the role of genetics in dissociative symptomology observed some evidence of a relationship between depersonalisation and derealisation experiences with specific genes (Rajkumar, 2022). Meanwhile, environmental factors such as increased online activity use have been associated with a greater amount of depersonalisation experiences (Ciaunica et al., 2022).

The freeze response, trauma and depersonalisation/derealisation

More recently literature has begun to acknowledge and demonstrate a relationship between trauma and dissociative disorders such as depersonalisation (Senior et al., 2001; Murphy, 2023) and this is now recognised in the DSM-5 (APA, 2013). Psychoanalytic theory understands DPDR as the brain’s adaptive response to acute stress and danger.(Simeon & Abugel, 2006; Swaim, 2022; Marschall, 2024). In order to survive, life-threatening experiences, such as abuse, the body may experience hyperarousal triggering the fight or flight response to help fight or run away from the threat (Gillette, 2021). Alternatively, some people become caught between the “fight or flight” response, triggering a freeze response which results in hypoarousal and a shutdown of the body, physically and mentally, until the danger has passed (Gillette, 2021). Future perceived threats may trigger a dissociative response as this has been successful in helping the person survive in the past (Gillette, 2021).

The freeze response has also been evidenced to result in physiological changes in the body and a biological theory proposes that it is these physiological changes which trigger depersonalisation and derealisation. A freeze response activates the parasympathetic path of the nervous system (Roelofs, 2017). During the freeze response, activity increases in the periaqueductal grey, the motor cortex and the right inferior frontal gyrus and heart rate decreases (Hermans et al., 2013; Roelofs, 2017). Similar physiological changes occur in the dissociative subtype of PTSD which is associated with the freeze response. The National Center for PTSD (2025) states that the dissociative subtype of PTSD is defined by derealisation and depersonalisation experiences. Those who re-experience symptoms through hypoarousal, typical of the dissociative subtype of PTSD, engage in "emotional overmodulation" which includes increased activity in the prefrontal cortex, reduced activity in the amygdala and a slow heart rate (Lanius et al., 2010; Murphy, 2023). Alternatively, those who re-experience symptoms through hyperarousal, typical of the non-dissociative subtype of PTSD engage in "emotional undermodulation" which includes increased activity in the amygdala, a faster heart rate and lowered activity in the prefrontal cortex (Lanius et al., 2010; Murphy, 2023). Consequently, those who respond to traumatic events by freezing may be more likely to experience depersonalisation and derealisation, possibly due to specific changes in their physiology. Nevertheless, Hermans et al. (2013) and Roelofs (2017) also found that amygdala activity increases during the freeze response. This was in contrast to Lanius et al. (2010) and Murphy (2023) who evidenced reduced amygdala activity in emotional overmodulation, present in the dissociative subtype of PTSD. Consequently, it still remains unclear how the brain's biological changes influence depersonalisation and derealisation experiences.

Studies have shown that people who experience particularly frightening and dangerous events, may develop PTSD and be more likely to re-experience their trauma (NHS, 2022). This may be because the freeze response has been observed to be stronger in people who have experienced adverse events (Roelofs, 2017) and is a typical adaptive response to abuse and trauma (Katz et al., 2021). For example, a study of the freeze response in people with previous exposure to adverse life events showed that participants who had exposure to more than one adverse event had stronger bodily reactions associated with the freeze response (Hagenaars et al., 2012). The freeze response attempts to control the abuse or life-threatening situation from getting worse (Davis, 2022). One particular type of trauma that has shown strong associations with depersonalisation and derealisation is childhood abuse (Yang et al., 2023). For example, Simeon et al. (2001) discovered that interpersonal abuse in childhood predicted higher scores on measures of depersonalisation and indicated an overall diagnosis of depersonalisation. Emotional abuse was the most likely type of abuse to cause experiences of depersonalisation as measured by the DES and Childhood Trauma Interview (Simeon et al., 2001). Meanwhile, data collected by the Longitudinal Studies of Child Abuse and Neglect (LONGSCAN) to examine the impact of different types of abuse and dissociative experiences in children aged eight to 12 years old found that children who had experienced more than one type of abuse, for example physical and sexual, showed increased experiences of depersonalisation and derealisation compared to those who had only been exposed to one type of abuse (De Silva et al., 2015). These studies indicated that experiences of abuse during childhood are likely to produce clinically significant symptoms of depersonalisation and derealisation, possibly due to the triggering of the freeze response and subsequent physiological reactions and therefore warrants further exploration.

Other types of trauma have also been shown to increase experiences of dissociation. For example, individuals who have survived a disaster such as an earthquake are more likely to score highly on measures of dissociation (Canan & North, 2019). Additionally, PTSD symptoms were observed to be worsened by peritraumatic dissociation (including depersonalisation and derealisation) following motor vehicle accidents (Hodgson & Webster, 2011). Furthermore, a study by Heydrich et al. (2019) showed that individuals who had frontal lobe epilepsy experienced depersonalisation whilst individuals who had temporal lobe epilepsy experienced derealisation. Despite these varied experiences of singular trauma, there still appears to remain a complex element to the development of depersonalisation and derealisation symptoms. For example, those who have experienced "previous emotional vulnerability factors" (Hodgson & Webster, 2011, p.218) are more likely to develop peritraumatic dissociation following their motor vehicle accident. Similarly, it has been suggested that positive associations observed between neurological impairment and DPDR are possibly "mediated" by interpersonal or developmental trauma (Murphy, 2023). This is because childhood trauma or adverse events do not fit with the person's template for their internal working model (Murphy, 2023). To survive this, the brain shuts down its connection to the self and body in an attempt to get rid of the distressing memories, resulting in dissociative experiences (Murphy, 2023). When traumatic events arise again, dissociation is an attempt to reduce physiological arousal and anxiety (Murphy, 2023). Depersonalisation and derealisation experiences continue after the threat, in response to the distress caused by depersonalisation and derealisation and the re-triggered memories (Hunter et al., 2003; Murphy, 2023). Consequently, it is evident that early developmental trauma may result in the development of depersonalisation and derealisation as a protective strategy. It is then this strategy which is subsequently re-triggered in later singular traumatic events.

Factors in DPDR expression

Following on from this research, some studies have started to focus on whether other factors such as sociodemographics or psychopathology (i.e. depression or anxiety) play a role in depersonalisation/derealisation experiences. An early study by Lee et al. (2012) investigated this with a dataset of 3275 people who had taken part in a birth study on health and development. Of the sample of 3275 participants, 33 were labelled as meeting the criteria for depersonalisation disorder in adulthood. There was no relationship between factors such as sociodemographic status or childhood depression but there was a link between childhood anxiety reported by teachers and depersonalisation in adulthood (Lee et al., 2012). Additionally, a relationship between clinical levels of adulthood anxiety and depression and depersonalisation disorder was discovered (Lee et al., 2012). Recent research into DPDR has been associated with PTSD (Armour et al., 2014), bipolar disorder (Hariri et al., 2015), depression (Bertule et al., 2021) and psychotic like experiences (O'Neill et al., 2021) suggesting that DPDR may be associated with certain pathological populations. A case series study investigated characteristics of a sample of 223 people with a DPDR diagnosis, finding that these individuals were younger, had an earlier onset of the symptoms and had reached greater levels of education than a sample of clients with a depression diagnosis (Michal et al., 2016). This study supports Campbell's (2021) assertion that the average age to start experiencing depersonalisation/derealisation is 16 years old with most having their first experience during childhood. However, this sample of people with DPDR, reported less childhood trauma and were more likely to be male which was not in line with previous findings affirming that women are likely to experience DPDR at double the rate of men (Campbell, 2021). This suggests that further research is required to investigate how DPDR occurs in different populations and the effect this has on the presentation of the disorder.

Theoretical models of DPDR

To better understand DPDR, Hunter et al. (2003) proposed the cognitive model of DPDR. The cognitive model of DPDR suggests that typical experiences of DPDR are catastrophically appraised and misinterpreted, with people incorrectly perceiving situations as extremely threatening or dangerous (Hunter et al., 2003). As a consequence, these people become stuck in a vicious loop of anxiety which increases over time leading to chronic DPDR (Hunter et al., 2003). The DPDR is subsequently maintained through avoidance, safety behaviours and cognitive biases (Hunter et al., 2003). For example, people with DPDR typically avoid social situations due to increased experiences of DPDR (Hunter et al., 2003). This was evidenced in a study by Simeon et al. (1997) who found that over half their participants with DPDR also met the diagnostic criteria for social phobia. Moreover, 90% of a sample of people with a social phobia diagnosis also had co-occurring experiences of depersonalisation (Hoyer et al., 2013). DPDR is reinforced by avoidance of social situations as this perpetuates the felt sense of detachment and isolation created by DPDR (Hunter et al., 2003). Similarly, people with DPDR develop safety behaviours which help them to fit in with typical members of society, however, their feeling of being different to others still remains inherent, strengthening the DPDR (Hunter et al., 2003). Moreover, thought biases mean that people with DPDR might engage in obsessive checking of their experiences of DPDR, bringing more focus and awareness of the symptoms and maintaining the illness (Hunter et al., 2003).

Another theoretical model of DPDR, states that understanding the role of the self is essential to understanding the disorder. Depersonalisation and derealisation experiences occur when there is a great amount of attention focused on the self (Jaspers, 1997). This hyperfocus or obsessive attention on the self is likely to increase DPDR experiences (Soffer-Dudek, 2023). Bodily signals that are processed by the brain malfunction, impairing the experience of senses and the way the world is interpreted, reinforcing the self-detachment (Ciaunica, Charlton & Farmer, 2021). These changes in the way the world is processed create a heightened awareness of the self at all times (Ciaunica, Charlton & Farmer, 2021). Ciaunica, Charlton and Farmer

(2021) liken this to “the way that cracks in otherwise transparent glass may indicate the presence of a previously unnoticed window” (p.15). A crack does not make the window disappear but instead changes the perception of the window (Ciaunica, Charlton & Farmer, 2021). Similarly, when bodily senses are altered and processed differently, the body does not disappear but instead shifts the perception of the self. If the impairment in processing of bodily signals continues, the DPDR experiences are maintained too. It is our tactile experiences which create an invisible connection to the world (Ciaunica, Roepstorffm et al., 2021). Hence, when bodily signals are not processed properly, a person may lose this invisible connection, resulting in DPDR experiences and the sense of detachment from the body, the self and the world (Ciaunica, Roepstorff, et al., 2021). Therefore, further exploration of the role of the self in relation to depersonalisation and derealisation experiences is important.

Conclusion

Compared with other psychopathologies, such as depression and anxiety, research exploring aetiological factors and how the disorder is experienced is still limited. Although the existing literature indicates a relationship between adverse childhood experiences and depersonalisation/derealisation experiences, little is known about how specific childhood experiences contribute to depersonalisation/derealisation or how factors such as self-concept clarity, gender and religion may shape these relationships. Moreover, research has not explored if there is a difference in the relationships between familial and non-familial types of childhood trauma and depersonalisation/derealisation experiences. In addition to this, qualitative evidence centring on individuals lived experiences of DPDR is scarce. A qualitative exploration of DPDR can provide a rich and critical insight into how DDPR is felt and interpreted, what maintains the disorder, barriers to care and unmet service user needs. By exploring DPDR, combining a quantitative and qualitative approach, richer data can be gathered which can contribute to better screening tools and improved treatment guidelines. In the long-term this can support healthcare professionals to identify those at risk of developing DPDR and ensure access to early interventions. Consequently, this study aimed to explore the lived experience of DPDR with a particular focus on the relationship between familial and non-familial adverse childhood experiences and depersonalisation/derealisation experiences and potential moderating and mediating factors, using a combination of quantitative and qualitative methodology. This study intends to answer the following questions:

1. How do adverse childhood experiences affect the development of depersonalisation and derealisation?
2. Do religion and gender play a role in the relationship between adverse childhood experiences and depersonalisation and derealisation?
3. How does self-concept clarity affect experiences of depersonalisation and derealisation, including the relationship between adverse childhood experiences and depersonalisation and derealisation?
4. What first-hand accounts of depersonalisation and derealisation can people with a diagnosis of DPDR provide?
5. How do these first-hand accounts inform understanding of DPDR and potential treatment recommendations?

Overview of the thesis

The current chapter continues below with a systematic review exploring the relationship between interpersonal abuse and DPDR. The systematic review appraises studies which employed reliable and valid measures to assess adverse childhood experiences and experiences of depersonalisation and derealisation. The systematic review aims to provide information from existing literature about the relationship between interpersonal abuse including interpersonal abuse experienced during childhood and depersonalisation and derealisation. The researcher hoped to select similar outcome measures used in the appraised papers for this study in order to address the aims of the research.

The overall thesis employed a mixed methods approach, conducting two studies. Chapter two will present an initial study utilising a quantitative approach. The quantitative study will provide data gathered from a large survey about adverse childhood events, depersonalisation and derealisation experiences and self-concept clarity; “the extent to which self-beliefs are clearly and confidently defined, internally consistent, and stable” (Campbell et al., 1996, p.141). In addition to this, demographic information will provide details about participants' religion and gender. Appropriate statistical analysis will be conducted to understand how adverse childhood events influence experiences of depersonalisation and derealisation and how this relationship may be moderated by religion and gender and mediated by self-concept clarity.

Chapter three presents a qualitative study to better understand the quantitative data gained from the initial study. The qualitative study will ask participants about their experiences of adverse childhood experiences or trauma, their sense of self and strategies that may be considered as protective against DPDR. Participants will also be asked to provide first-hand accounts of their journey to receiving a diagnosis for DPDR. Thematic analysis will be used to elicit valuable first-hand information that supports healthcare professionals to better understand and treat DPDR.

The final chapter (Chapter 4, General Discussion) will consider the findings of both studies together and explore ways that they can help to better understand DPDR. The discussion will acknowledge findings from the quantitative and qualitative studies which complement each other and other findings which require further exploration. Recommendations will be made for future clinical practice and areas where research may need to continue. The theory of DPDR will also be reappraised in the context of the overall study findings.

The relationship between interpersonal abuse and depersonalisation-derealisation disorder (DPDR): A Systematic Review'

Researchers in the field of depersonalisation and derealisation indicate that there is evidence of an association between depersonalisation and derealisation experiences and interpersonal abuse, yet, more research is required to better understand this relationship and confirm the extent of the relationship (Simeon et al., 2001 & Yang et al., 2023). First, it is important to understand the definition of interpersonal abuse. Interpersonal abuse or violence is defined as "the intentional use of physical force or power against other persons by an individual or small groups of individuals" (Mercy et al., 2017, p.71). Mercy et al. (2017) outline that this can take the form of psychological, physical or sexual abuse and can be committed within families, for example between partners, or in the community, such as through bullying. Deprivation and neglect are also included in the definition of interpersonal abuse (Mercy et al., 2017). The terms interpersonal abuse and interpersonal violence are used interchangeably in literature and so this review will also make reference to both.

Interpersonal abuse emphasises abusive behaviours within a relational context (Center for Survivors, n.d.). It can affect anyone at any stage in life, however, it is commonly experienced during childhood (Walby & Allen, 2004). Those who have experienced interpersonal abuse during childhood are more at risk of requiring psychiatric support for mental health difficulties compared with peers who have not had exposure to interpersonal abuse (Marshall et al., 2020). A study by Glisson and Green (2006) investigated the rate of mental health and behavioural difficulties in a population of children in the child welfare or criminal justice system, many of whom had been exposed to interpersonal abuse. They discovered that 64% of the children had high rates of these difficulties which would be suitable for a medical intervention. Similarly, Iverson et al. (2013) demonstrated that interpersonal violence experienced by both men and women was correlated with increased risk of mental health difficulties and suicide. Specifically, these mental health difficulties included anxiety, mood disorders, substance use difficulties, and PTSD (Iverson et al., 2013). A further study by Vertommen et al. (2018) explored the impact of interpersonal abuse on mental health in a sample of athletes who had been exposed to psychological, sexual and physical abuse during their childhood. They discovered that experience of these types of abuse during childhood increased mental health difficulties in adulthood, such as anxiety, depression and somatisation (Vertommen et al., 2018). Additionally, participants' quality of life during adulthood was assessed to be poor (Vertommen et al., 2018). Hence, there is a clear link between interpersonal abuse and mental health difficulties.

Dissociative experiences have often been associated with experiences of interpersonal abuse. This is because dissociation is a mechanism triggered during the evolutionary ‘fight, flight, freeze’ response which is likely to be activated during interpersonal abuse, as described earlier. Granieri et al. (2018) explains that dissociation becomes all-encompassing and affects mental health when there is exposure to numerous traumatic events. In the case of interpersonal abuse, such as domestic violence, victims tend to be exposed to more than one instance of abusive behaviour (Hester, 2013; Weir 2024). In a study by Felson et al. (2005) 17% of participants were exposed to repeated victimisation, whilst a study by Bland & Ariel (2015) discovered this figure was higher at 32%. This suggests that those who have experienced interpersonal abuse may be at higher risk of repeated incidents of victimisation, leading to increased triggers for dissociative experiences, subsequently impacting on their mental health. This has been evidenced by Shim et al. (2024) who found that dissociative experiences have a mediating role in the association between interpersonal trauma and symptoms of depression. Lundin (2024) affirms that “dissociative experiences represent one of the significant outcomes of childhood adversity” (p.V). Lundin (2024) discovered that participants who had experienced severe episodes of maltreatment during childhood were more likely to have higher scores of dissociation in adulthood. Similarly, studies or meta-analyses by Vonderlin et al. (2018), Thal et al. (2019) and Myers and Llera (2020) have all demonstrated a relationship between childhood interpersonal abuse and more intense experiences of dissociation in adulthood. This indicates that interpersonal trauma, particularly when experienced during childhood, is related to dissociative experiences later in life.

One type of dissociative experience which has shown a relationship with interpersonal abuse is depersonalisation and derealisation. A study by Aponte-Soto et al. (2019) investigated the prevalence of depersonalisation as a symptom in a group of 40 adults with a history of interpersonal abuse, compared with a control group of 40 healthy individuals. Aponte-Soto et al. (2019) found that those with interpersonal abuse experiences had significantly higher scores on the Cambridge Depersonalisation Scale (CDS; Sierra & Berrios, 2000). Furthermore, Aponte-Soto et al. (2019) discovered that a quarter of the interpersonal abuse group had a score of 70 or more, indicating the clinical presence of DPDR as determined by Sierra & Berrios (2000). Despite this, no participant had a formal diagnosis of DPDR (Aponte-Soto et al., 2019). Similarly, Michal et al. (2007) explored the relationship between emotional maltreatment and the severity of depersonalisation experiences in participants with and without long-term nonmalignant pain. Michal et al. (2007) evidenced a significant relationship between emotional maltreatment and the severity of depersonalisation experiences in the participants who did not experience long-term nonmalignant pain. Additionally, a recent case study of a patient with experience of parental verbal abuse evidenced high scores on measures of depersonalisation and derealisation suggesting clinically significant DPDR (Frau & Corrigan, 2025). Frau & Corrigan (2025) propose that sudden distressing experiences such as interpersonal abuse triggers a stress response which disrupts the typical functioning of the cortex. As a consequence of this disruption, depersonalisation experiences are produced (Frau & Corrigan, 2025). Until this imbalance in the brain is resolved, depersonalisation experiences are likely to persist (Frau & Corrigan, 2025). Given this understanding that interpersonal abuse may be responsible for triggering depersonalisation and derealisation experiences, an exploration of this relationship with DPDR itself is certainly warranted.

Finally, as with depersonalisation and derealisation experiences, the dissociative subtype of PTSD has also been shown to relate to interpersonal abuse. The main distinction between the dissociative subtype of PTSD and DPDR is the presence or absence of symptoms of PTSD, as per the DSM-5 criteria (Spiegel, 2023; Spiegel, 2025). For example, individuals who have been directly exposed to a traumatic event and experience recurrent and distressing flashbacks alongside dissociative experiences such as depersonalisation and derealisation would likely meet criteria for the dissociative subtype of PTSD (APA, 2013). A study by Gidzgier et al. (2019) assessed 258 females with diagnoses of substance use disorder and PTSD. They conducted a latent class analysis discovering three classes within the participants (Gidzgier et al., 2019). The first class was named the dissociative subtype of PTSD and was characterised by childhood emotional abuse, childhood sexual abuse, childhood emotional neglect, significant experiences of dissociation, severe PTSD, depression and borderline personality disorder, greater than those in the other two classes (Gidzgier et al., 2019). Class two were named “high symptomatic childhood trauma class” and had experienced high levels of overall trauma during childhood which were related to high levels of current depression (Gidzgier et al., 2019). Meanwhile, class three labelled “low symptomatic childhood trauma class” had less experiences of childhood trauma than class two and reported lower levels of current depression (Gidzgier et al., 2019). The dissociative subtype of PTSD class had particularly higher incidences of sexual abuse during childhood than the other two classes, suggesting that this specific type of interpersonal abuse may play a role in eliciting dissociative experiences related to the dissociative subtype of PTSD. Similarly, King et al. (2020) carried out a study of 106 women with a diagnosis of PTSD who were engaging in a programme offering psychiatric care for disorders related to trauma (King et al., 2020). These women completed self-report measures including the PTSD Checklist for DSM-5 (PCL-5; Weathers et al., 2013), the Dissociative Subtype of PTSD Scale (DSPS; Wolf et al., 2017) and the Childhood Trauma Questionnaire (CTQ; Bernstein et al., 1994). After analysis using multivariate linear regression, King et al. (2020) found that individuals who had experienced emotional and physical abuse during childhood were more likely to experience depersonalisation and derealisation, with emotional abuse being the most significant predictor of these experiences. Additionally, a latent profile analysis of the DSM-5 dissociative subtype indicated that severe PTSD was associated with the dissociative subtype of PTSD (Frewen et al., 2015). Moreover, those who were identified as having severe PTSD also reported histories of childhood abuse, namely physical and sexual (Frewen et al., 2015). Consequently, there is clear evidence that experiences of interpersonal abuse are associated with the dissociative subtype of PTSD which is characterised by additional depersonalisation and derealisation experiences.

Although the body of literature described above suggests that a relationship between depersonalisation and derealisation experiences and interpersonal abuse exists, there has been no specific study exploring the possible relationship between interpersonal abuse and DPDR. Yang et al. (2023) did conduct a systematic review investigating the presence of DPDR across different samples, finding that the sample of participants who had experienced interpersonal abuse showed the highest rates of this disorder. In comparison to a prevalence rate of DPDR at 1% amongst a non-clinical population, prevalence rates of DPDR amongst participants with interpersonal abuse experiences were approximately 25% to 50% higher (Yang et al., 2023). This indicated that people with interpersonal abuse were more likely than any other group to develop DPDR. Given these important findings, Yang et al. (2023) advised that the relationship between interpersonal abuse and DPDR should be explored further to better understand the nature of this relationship. Therefore, this systematic review intended to build on Yang et al's. (2023) findings and explore the novel relationship between interpersonal abuse and participants clinically diagnosed with DPDR. The review hoped to provide further information about the risk of people with experiences of interpersonal abuse developing DPDR and reasons for this increased risk. The review intended to answer the following question:

Are people who are exposed to interpersonal abuse at increased risk of developing clinical DPDR?

The reviewer hypothesised that experiences of interpersonal abuse would increase the risk of developing clinical DPDR.

Methodology

Search terms

The PEO (population, exposure of interest and outcome) review protocol was followed and determined the search concepts as the review posed an aetiological question. Searches focused on studies including any person (population) who had been exposed to interpersonal abuse (exposure) and developed DPDR (outcome). The reviewer used Mercy et al's (2017) definition of interpersonal abuse to help clarify the search terms for the exposure concept. The literature indicated that the term interpersonal abuse could be interchanged with the term intimate abuse. The terms interpersonal and intimate were therefore used in the exposure search to ensure that these types of abuse and relationships were identified. For each search concept, the Boolean operator "OR" was used. For the final search, the Boolean operator "AND" combined the population search (adult*, child*, girl*, boy*, women, men, man, woman), exposure search (abuse, maltreatment, violen*, intimate, interpersonal) and outcome search ("depersonalisation-derealisation disorder", "depersonalization-derealization disorder", depersonalisation disorder, depersonalization disorder, depersonalisation derealisation syndrome, depersonalization derealization syndrome). Quotation marks, English and American spellings and truncation were used to ensure that all relevant literature was reviewed.

Inclusion/exclusion criteria

During the initial search for papers, the reviewer excluded studies published before1992. The ICD-10 was published in 1992, becoming the first diagnostic manual to use the term depersonalisation-derealisation. Prior to this, depersonalisation-derealisation had just been known as depersonalisation and although derealisation was acknowledged as a symptom, it had not been considered a separate feature that could exist separately from depersonalisation. The reviewer therefore specifically wanted to investigate DPDR as defined by the newer diagnostic terms. Foreign language papers were also excluded to ensure that all information in the papers was understood by the reviewer. During the review of the papers, further inclusion and exclusion criteria were applied based on study design, publication type, population and outcome. The full inclusion and exclusion criteria is outlined below (Table 1.1).

Table 1.1

Initial Search Inclusion/Exclusion Criteria

Inclusion	Exclusion
Studies published between January 1992 and 2025	Studies published before 1992
English language papers only	Foreign language papers
Depersonalisation-derealisation as a disorder	Depersonalisation and derealisation as symptoms Dissociative subtype of PTSD Dissociation
Studies adopting a quantitative or mixed method approach to assessing DPDR and interpersonal abuse (e.g validated outcome measures)	Studies adopting a solely qualitative approach to assessing DPDR and interpersonal abuse (e.g. interviews)
Study design Case series Case-control Cross-sectional	Study design Case studies Systematic reviews Meta-analyses
-	Other literature i.e. books or articles
Participants exposure to interpersonal abuse	Participants exposure to other traumatic events which were not considered to be interpersonal abuse (e.g. exposure to a natural disaster)
Papers that assessed the link between DPDR and interpersonal abuse	Papers that did not assess the link between DPDR and interpersonal abuse

Procedure

A single reviewer completed the systematic review. The PRISMA flow diagram (Figure 1.1) provides an illustrative summary of the search process. In April 2025, four online database searches (APA PsycArticles, APA PsycInfo, CINAHL & Medline), a grey literature search of

ProQuest and two citation searches on SCOPUS amounted to retrieval of 752 articles which were exported onto the computer programme Rayyan (Ouzzani et al., 2016). All papers were screened for duplicates, of which 222 were identified and removed. Titles and abstracts only of the remaining 530 papers were appraised and a further 494 were deemed to not meet the inclusion criteria (Table 1.1) and hence were discounted. A total of 36 papers were categorised as include or maybe include following appraisal of the abstracts. Papers marked as maybe indicated that there was some exploration of the relationship between depersonalisation and derealisation and interpersonal abuse but it was not clear from the abstract whether the participants had received a clinical diagnosis of DPDR. The full paper for each of these studies were subsequently sought and reviewed. After reading each paper fully and applying the inclusion and exclusion criteria (Table 1.1), a further 18 papers were discounted as it was clear that there was no clinical diagnosis, whilst eight papers were included due to meeting the inclusion criteria. Ten papers identified remained classified as maybe due to uncertainty about whether participants had received a clinical diagnosis of DPDR. The reviewer had a further discussion with their supervisor to clarify how clinical diagnosis could be determined. The reviewer and supervisor agreed that it was appropriate to include any studies where a diagnosis had been provided following a clinical interview or present state examination with a trained clinician either prior to or at the start of the study. Scoring above the clinical cut-off on depersonalisation questionnaires was not deemed suitable without an additional clinical interview. Another review of the papers led to a further eight papers excluded and two papers included. This resulted in a total of 10 papers to be included in the review.

Quality Assessment

The Joanna Briggs Institute (JBI) critical appraisal checklist for prevalence data was used to check the quality of most of the final papers retrieved (appendix A). This is an appropriate and simple tool for checking quality in studies investigating prevalence data (Munn et al., 2014; Migliavaca et al., 2020). The checklist reviewed study design and procedure in addition to analysis of data. In addition to this quality tool, the reviewer also used the JBI critical appraisal tool to appraise the methodological quality (Munn et al., 2020) of the two case series studies by Song et al. (2014) and Michal et al. (2016). It was appropriate to use more than one quality appraisal checklist due to the diversity of study types retrieved (University Libraries, 2022).

Quality was assessed by answering the checklist questions with yes, no, unclear or not applicable (appendix B; appendix C). Overall quality was appraised by the reviewer opting to include, exclude or seek further information about the paper. Munn et al. (2020) do not provide advice about the appropriate cut-off score for inclusion in a systematic review. Instead, they advise that it is up to the reviewer to decide cut-off values for level of quality when using JBI critical assessment tools (Munn et al., 2020). Hence, the reviewer for this study decided that papers which had received yes answers on at least five items on the checklist were to be included in the study, as at least 50% of the checklist was considered to be good quality. The reviewer proposed that moderate quality papers had five or six checklist items marked yes, good quality papers had seven or eight checklist items marked yes and excellent quality papers had nine or ten items marked yes.

Data Extraction

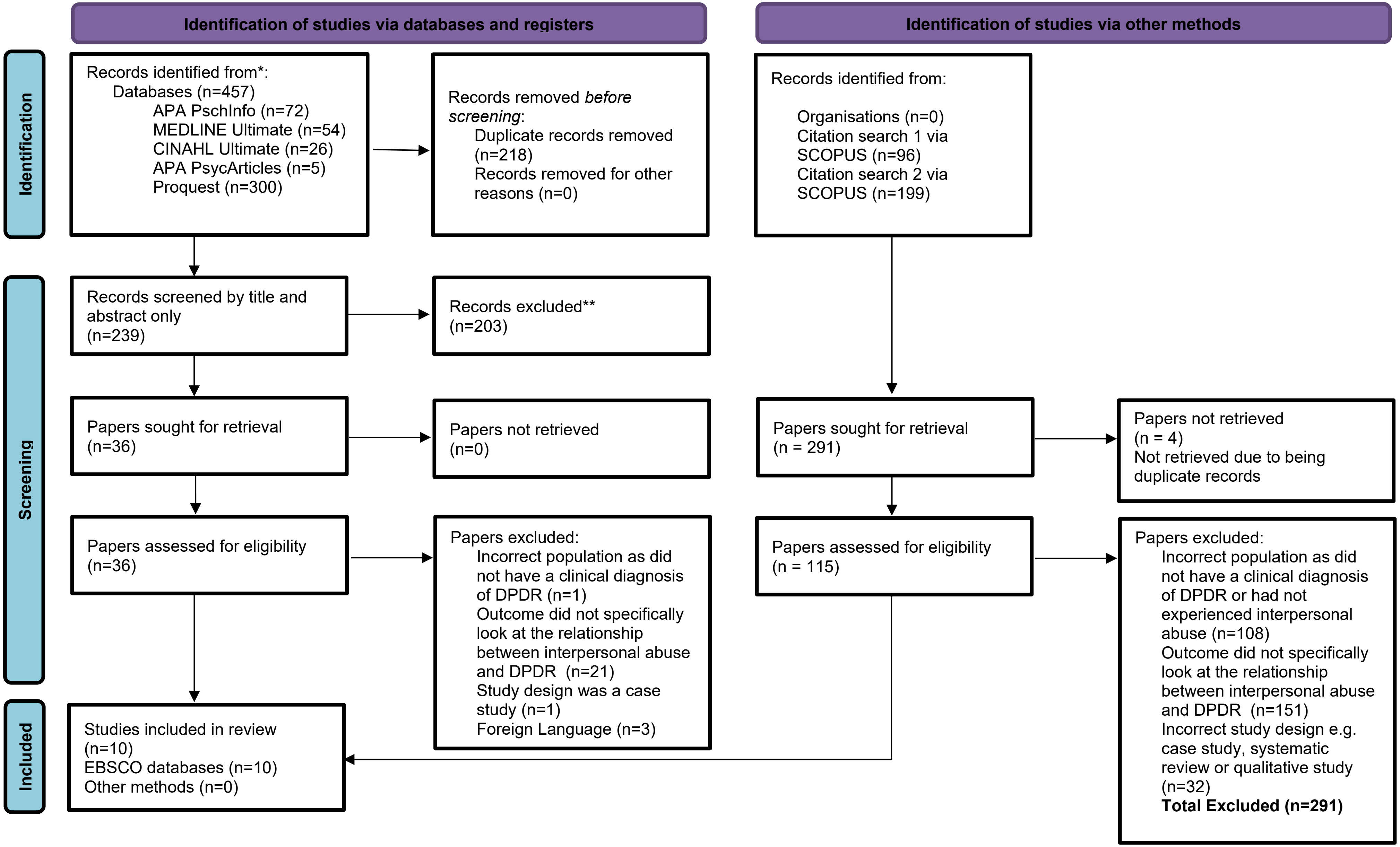
The reviewer designed data extraction tables based on guidance by Fleeman and Dundar (2017). Fleeman and Dundar (2017) advise extracting data pertaining to study design, place of study, sample size, outcomes of the study and study sponsorship. They also discuss the importance of gathering demographic information relating to participants, such as age and gender (Fleeman & Dundar, 2017). The reviewer split this information into three different tables, pertaining to study characteristics (Table 1.2), sample characteristics (Table 1.3) and a preliminary synthesis of the method and results from each eligible study (Table 1.4). The reviewer initially focused on synthesising information related to study characteristics and sample characteristics allowing them to become familiar with the study. Analysis methods and outcomes for each study were reported. Data that did not address the research question of the systematic review were excluded. For example, data analysis regarding the relationship between alexithymia and DPDR in the study by Simeon, Giesbrecht et al. (2009) was not reported as this was not the focus of the current systematic review.

Synthesis

Whilst there was some methodological and clinical homogeneity, this was not enough to conduct a meta-analysis (McKenzie & Brennan, 2019). In place of a meta-analysis, Campbell et al. (2020) recommend a textual narrative synthesis. Popay et al. (2006) explain that a narrative synthesis can help to synthesise findings of the studies, focus on patterns within the data from the studies and evaluates the robustness of the synthesis itself. Furthermore, Moola et al. (2015) suggest that in a review focusing on aetiology, a narrative synthesis can provide textual information when participants, data and method in the selected studies are dissimilar. A narrative synthesis approach can instead rely on interpretation and reflexivity, helping to synthesise meaning from the data (Moola et al., 2015).

Figure 1.1

PRISMA 2020 flow diagram



Results

Study Characteristics

A total of 10 studies were selected for review. The study papers were published over a 27-year time span, between 1997 and 2024. Half (50%) of the studies had been published in the last 10 years. Publication dates of the studies ranged between 2014 and 2022 with most (70%) published in the last five years. Studies were conducted across a wide range of countries and participant nationalities including China, Germany, America, Turkey and the United Kingdom (Table 1.3). This meant that the studies were able to look at the experiences of people with DPDR with diverse cultural backgrounds.

Some of the studies recruited participants with a diagnosis of DPDR whilst half (50%) of the studies also confirmed a DPDR diagnosis for participants at the start of the study. A diagnosis was made by a qualified clinician using the Structured Clinical Interview for DSM-IV Dissociative disorders (SCID-D; Steinberg et al., 1993). All the studies used outcome measures or clinical interviews to further quantify clinical DPDR experiences. Seven (70%) papers utilised the Dissociative Experiences Scale (DES; Carlson & Putnam, 1993) and a further five (50%) papers used the Cambridge Depersonalisation Scale (CDS;Sierra & Berrios, 2000) or a variation of this outcome measure to measure experiences of depersonalisation and derealisation.

To measure interpersonal abuse the Childhood Trauma Questionnaire (CTQ;Bernstein et al., 1994) was the predominant measure, used in seven (70%) of the studies. Most of the studies investigated relationships between responses on the trauma questionnaires and results of depersonalisation and derealisation outcome measures. Six (60%) of the studies were designed as a case control and hence compared these results with participants in healthy control groups. This made these studies more easily comparable. A full summary of the study characteristics is outlined in Table 1.2.

Five (50%) of the papers had the same lead researcher, Daphne Simeon. These studies also shared one further common researcher, Margaret Knutelska.

Table 1.2

Summary of study characteristics

Authors & Year of publication	Country	Study Design	Study Sponsorship	Outcome Measures and Interviews
Song et al. (2014)	China	Case series	Beijing Hospitals Authority Clinical Medicine, Beijing Hospitals Authority Youth Program & Beijing Hospitals Authority's Ascent Plan	CDS[a] DES[b] CTQ[c]
Simeon & Knutelska (2022)	Not stated	Case-control	None	SCID-D[d] DES CTQ
Thomson & Jaque (2018)	USA	Cross-sectional	None	DES-II depersonalization subscale CDS

				MDI[e] ACE[f] TEQ[g]
Authors & Year of publication	Country	Study Design	Study Sponsorship	Outcome Measures and Interviews
Sar et al. (2017)	Turkey	Case-control	None	Steinberg Depersonalization Questionnaire (SDEPQ)[h] Steinberg Derealisation Questionnaire (SDERQ) SCID-D CTQ
Lee et al. (2012)	UK	Cross-sectional	Department of Health via the National Institute for Health Research Specialist Biomedical Research Centre for Mental Health award to South London and Maudsley NHS Foundation Trust and The Institute of Psychiatry at	Present State Examination

			King's College London. The Medical Research Council Training Fellowship.	

Authors & Year of publication	Country	Study Design	Study Sponsorship	Outcome Measures and Interviews
Simeon et al. (1997)	USA	Case-control	None	Semi-structured interview[i] SCID-D DES Childhood Antecedents Questionnaire A semi-structured interview rating types of childhood trauma
Simeon et al. (2001)	USA	Case-control	National Institute of Mental Health (NIMH) grant	SCID-D DES Childhood Trauma Interview
Simeon et al. (2008)	USA	Case-control	National Institutes of Health (NIH) grants RO1 MH62414 and MO1 RR0071	Standard clinical interview[j] SCID-D DES CDS SDQ[k] CTQ-Short form

Authors & Year of publication	Country	Study Design	Study Sponsorship	Outcome Measures and Interviews
Simeon, Giesbrecht, et al. (2009)	USA	Case-control	NIMH grant, NIH grant and the Netherlands Organization for scientific research	SCID-D DES CDS CTQ
Michal et al. (2016)	Germany	Case series	None	Clinical interview[l] CDS-2[m] CTQ

Note. Only the outcome measures used to assess interpersonal abuse and DPDR experiences are reported in the table above.

[a] Cambridge Depersonalisation Scale

[b] Dissociative Experiences Scale

[c] Childhood Trauma Questionnaire

[d] Semi-structured Clinical Interview for Dissociative Symptoms and Disorder

[e] Multiscale Dissociation Inventory

[f] Adverse Childhood Experiences

[g] Traumatic Events Questionnaire

[h] The unpublished translated versions of the SDEPQ and SDERQ were used in Sar et al's. (2017) study.

[i] The semi-structured interview inquired about history of depersonalisation and was developed by the authors of the paper.

[j] The standard clinical interview was developed by Simeon et al. (2003).

[k] Somatoform Dissociation Questionnaire

[l] Diagnosis of DPDR was based on the ICD-10 diagnostic criteria.

[m] The two-item version of the CDS was used in Michal et al's. (2016) study.

Sample Characteristics

The papers included a wide range of samples between 30 (Simeon et al., 1997) and 3275 (Lee et al., 2012), reflecting the different study designs. However, many of the studies had smaller groups of participants with DPDR. Typically, DPDR groups had approximately 50 participants although two (20%) studies had DPDR groups of over 200 participants (Michal et al., 2016; Song et al., 2024).

The mean age of participants with DPDR ranged between 21 and 34 years old. Three (30%) of the papers reported a mean age of 31 whilst a further three (30%) papers established a mean age between 31 and 34 years old. In Lee et al's. (2012) study, the age of all participants was 36 years.

There was no clear pattern in the study samples regarding gender. Two (20%) of the papers reported a male majority sample in the DPDR group, whilst three (30%) of the studies stated a female majority sample. One (10%) further study had an equal split of male and female participants.

Age of onset of DPDR experiences was reported in six (60%) of the papers. Age of onset ranged between 16 and 22 years old. Sixteen years old was the most typical age of onset, recorded in four (40%) of the studies.

Participants were recruited to the studies via many different avenues. Samples were representative of the community, university students and from medical centres. A detailed summary of sample characteristics are reported in Table 1.3.

Table 1.3

Summary of sample characteristics

Authors & Year of publication	Sample size (n)	Sample	Mean Age (n)	Sex (n & %)	Age of onset of DPDR in DPDR group (n)
Song et al. (2024)	646	Patients with symptoms of DPDR, presenting consecutively to Beijing Anding Hospital outpatient clinic. Attended the outpatient clinic between April 2020 and June 2023 Participants were aged between 15 and 45 as per the inclusion criteria for the study. DPDR group 217 participants Comparison groups as follows: Generalised anxiety disorder (GAD) group – 110 participants Bipolar disorder (BD) group – 244 participants	24 (DPDR group)	144 (66%) males 73 (34%) females (DPDR group)	18.2

		Major depressive disorder (MDD) group – 75 participants			

Authors & Year of publication	Sample size (n)	Sample	Mean Age (n)	Sex (n & %)	Age of onset of DPDR in DPDR group (n)
Simeon & Knutelska (2022)	95	Recruited through community advertisements. Participants were aged between 18 and 60 as per the inclusion criteria for the study. DPDR group - 42 participants Control group – 53 participants	32 (DPDR group)	19 (45%) males 23 (55%) females (DPDR group)	Not reported
Thomson & Jaque (2018)	264	Recruited from university athletic and arts programmes, professional arts training programmes and word of mouth DPDR group – 43 participants	24 (DPDR group)	75 (28%) males 200 (76%) females (overall sample)	Not reported

		Group without DPDR – 221 participants		46.9% male and 53.1% female in the DPDR group	
Authors & Year of publication	Sample size (n)	Sample	Mean Age (n)	Sex (n & %)	Age of onset of DPDR in DPDR group (n)
Sar et al. (2017)	1301	Students at the Cumhuriyet University in Turkey Dissociative disorders group – 78 participants DPDR group – 12 participants Control group – 91 participants	21 (overall sample)	43 (55%) males 35 (45%) females (Dissociative disorders group)	Not reported
Lee et al. (2012)	3275	The National Survey of Health and Development in 1982 Participants consisted of people who were born to “married women with husbands in non-manual and agricultural employment [or] women	N/A – all participants were 36	1634 (50%) males 1641 (50%) females (overall sample)	Not possible to determine this

		with husbands in manual employment in England, Scotland and Wales from 1 week in March 1946" (Lee et al., 2012, p. 255) who subsequently answered questions about depersonalisation in 1982.			
Authors & Year of publication	Sample size (n)	Sample	Mean Age (n)	Sex (n & %)	Age of onset of DPDR in DPDR group (n)
Simeon et al. (1997)	30	27 participants were recruited via media advertisements 3 participants were recruited from clinician referrals The DPDR group were required to meet diagnostic criteria for DPDR through semi-structured interview and SCID-D. DPDR group – 30 participants	32 (DPDR group)	11 (37%) males 19 (63%) females (DPDR group)	16.1

		Control group – 20 participants			

Authors & Year of publication	Sample size (n)	Sample	Mean Age (n)	Sex (n & %)	Age of onset of DPDR in DPDR group (n)
Simeon et al. (2001)	75	Most subjects in the DPDR group were recruited from other studies including the pharmacological treatment study and the neurochemical challenge study. DPDR group were also recruited via newspaper advertisements and clinician referrals. The control group were recruited from neuropsychology and neurochemical challenges studies. Control group were additionally recruited via advertisements. DPDR group – 49 participants Control group – 26 participants	34 (DPDR group)	Not reported	16.1

Authors & Year of publication	Sample size (n)	Sample	Mean Age (n)	Sex (n & %)	Age of onset of DPDR in DPDR group (n)
Simeon et al. (2008)	101	DPDR group – 54 participants Control group – 47 participants DPDR group diagnosed via standard clinical interview and SCID-D Control group had no psychiatric disorders as established by a SCID.	31 (DPDR group)	25 (46%) Males 29 (54%) Females (DPDR group)	16.5
Simeon, Giesbrecht, et al. (2009)	102	DPDR group – 46 participants PTSD group without the dissociative subtype – 21 participants Control group – 35 participants DPDR and PTSD groups did not have any diagnosis of depression, substance use disorders, eating disorders, bipolar or psychosis.	31 (DPDR group)	23 (50%) males 23 (50%) females (DPDR group)	16.3

Authors & Year of publication	Sample size (n)	Sample	Mean Age (n)	Sex (n & %)	Age of onset of DPDR in DPDR group (n)
Michal et al. (2016)	1352	Outpatients from the department of psychosomatic medicine and psychotherapy at the university medical center Mainz in Germany. Most participants self-referred to the clinic, following internet research. All participants had a short interview via telephone before being seen for assessment. The comparison group patients self-referred or were referred by local health professionals, including a psychotherapist. DPDR group – 223 participants Depressive disorder group without comorbid DPDR – 1129 participants	31 (DPDR group)	125 (56%) males 98 (44%) females	22.9

	117 participants of the DPDR group consulted the DPDR clinic directly whilst the remaining 26 participants received their diagnosis and treatment from the general outpatient clinic.

Note. All figures in the table have been rounded to the nearest whole number, except for the final column which was rounded to 1.d.p.

Synthesis of Findings

Table 1.4 provides a summary of the key findings in each study.

Table 1.4

Preliminary synthesis of method and results from eligible studies

Authors & Year of publication	Method	Analysis	Results
Song et al. (2024)	● Participants identified and diagnosed with DPDR and placed in DPDR group ● Took part in interviews to gather sociodemographic and clinical information relevant to DPDR ● Completed outcome measures for assessment of depersonalisation and derealisation experiences, adverse childhood experiences, depression,	● Chi-square used for comparison of groups ● Kruskal-Wallis H test and ANCOVA for comparison of the diagnostic groups ● Friedman test to investigate statistical differences within the DPDR group ● Spearman's rank correlation ● Linear regression model	● Significant differences in scores in the DPDR group, on the factors of the CDS related to "Alienation from surroundings" and "Unreality of surroundings" ● DPDR group had lower levels of anxiety than the GAD group but higher anxiety levels than the BD group ● DPDR group had lower levels of depression than the GAD and MDD group ● One of the most commonly reported triggers for the onset of DPDR was family factors or events ● Over 90% of the DPDR group reported that DPDR symptoms were persistent ● Emotional neglect was the most reported adverse childhood experience, followed by physical neglect, emotional abuse, physical abuse and sexual abuse

	anxiety and psychosocial functioning		● A significant positive association between the total scores on the CTQ and the CDS was observed ● Significant positive correlations were also observed between the total CTQ scores and the CDS factors of “perceptual alterations”, “temporal disintegration” and “alienation from surroundings”

Authors & Year of publication	Method	Analysis	Results
Simeon & Knutelska (2022)	● Completed outcome measures for assessment of attachment, depersonalisation and derealisation experiences and childhood trauma	● Independent sample t-tests and chi-square tests to compare DPDR group and control group outcome measure scores ● Pearson’s zero-order correlations to investigate associations between variables of	● No differences in demographic characteristics between the two groups ● Evidenced an indirect effect of fearful attachment on severity of dissociation ● In the group of participants with DPDR, this indirect effect was mediated by scores on the CTQ ● Higher scores for quantity and severity of childhood trauma on the CTQ, in the DPDR group ● Emotional abuse and neglect were significantly elevated in the DPDR group

		attachment, dissociation and trauma ● Hierarchical regression analyses ● Hayes' PROCESS macro add-on version 3.5.3 to explore mediations	● All five categories of trauma were significantly related to typical experiences of dissociation in the DPDR group ● Emotional maltreatment was significantly related to clinical dissociation in the DPDR group
Authors & Year of publication	Method	Analysis	Results
Thomson & Jaque (2018)	● Completed self-report outcome measures ● Completed a second set of self-report outcome measures	● MANCOVA to investigate differences between the groups	● The DPDR group had more incidences of adverse childhood events ● Emotional abuse was the most commonly reported adverse childhood experience, followed by emotional neglect and divorce/separation ● Experience of physical abuse and family mental illness were also more common in the DPDR group

	six month after initial completion		● The DPDR group had significantly higher scores on the ACE and TEQ suggesting more exposure to traumatic events ● For the DPDR group, younger age and female gender were significant covariates for group differences including total ACE and TEQ scores ● The DPDR group had more experiences of emotional and physical neglect than the group without DPDR ● There were significant differences for family dysfunction during childhood and childhood abuse and neglect between those in the DPDR group and those without DPDR

Authors & Year of publication	Method	Analysis	Results
Sar et al. (2017)	● Outcome measures for trauma and dissociation completed at screening ● SCID-D carried out for BPD group and control group	● Spearman correlations ● Kruskal-Wallis test ● Stepwise regression analysis	● Dissociative Disorder (DD) group, including those with DPDR, had significantly greater SCID-D depersonalisation and derealisation scores than the non-DD group ● Moderate associations between the CTQ and SDEPQ in the DD group ● Moderate associations between the CTQ and SDERQ in the DD group

			● Emotional abuse, physical neglect and sexual abuse predicted the total score on the SDEPQ and SDERQ
Authors & Year of publication	Method	Analysis	Results
Lee et al. (2012)	● Class teachers of the participants at age 13 were asked about participants mood and attention ● At age 36, participants were administered the Present State Examination	● Logistic regression ● Reverse-stepwise method ● Wald test	● DPDR was related to the female sex, anxiety during childhood and increased levels of depression and anxiety during adulthood ● No associations were found between depersonalisation syndrome and adverse childhood events which included experiences of interpersonal abuse.
Simeon et al. (1997)	● DPDR group completed clinical interviews and outcome measures exploring dissociative experiences and childhood trauma	● Independent t-tests with Bonferroni correction ● Pearson's correlations	● Significant difference between control group and DPDR group on the total DES score and each factor score of the DES ● In the DPDR group, during childhood, ten (33%) participants had experienced sexual abuse, nine (30%) participants had experienced

	● Control group completed outcome measures related to dissociative experiences and childhood trauma	● Principal components factor analysis with varimax rotation	physical abuse and eight (27%) participants had witnessed domestic violence ● Significant differences were observed between the DPDR group and control group for physical abuse (t=2.03, df=48, p<0.05) ● Differences for witnessing domestic violence and sexual abuse between the two groups were not significant (p>0.05) although the sexual abuse scores did approach significance ● In the DPDR group, there were no significant associations between any of the categories of trauma or total trauma scores and factors or total scores on the DES ● A relationship between total trauma score and total DES score approached significance when the scores for the DPDR group and control group were combined together ● A relationship between total trauma score and score on the factor for depersonalisation/derealisation in the DES also approached significance when the scores for the DPDR group and control group were combined together

			- The participants in the DPDR group showed a significantly higher total trauma score as measured by the Childhood Antecedents Questionnaire than the control group

Authors & Year of publication	Method	Analysis	Results
Simeon et al. (2001)	- Initial telephone screening for potential participants - SCID-D administered - Completed outcome measures for dissociation and childhood trauma	- Independent t-tests with Bonferroni correction - Logistic regression analyses to explore if scores for trauma could predict diagnostic group - Multiple regression analyses to predict dissociative scores by scores on the trauma questionnaire	- Scores on the DES were significantly higher for the DPDR group than the control group - Total scores for separation or loss were significantly higher in the control group compared with the DPDR group - Total scores for emotional abuse were significantly higher in the DPDR group compared with the control group - Total trauma score was significantly greater in the DPDR group compared with the control group - Scores for the six different types of trauma were summed and correctly predicted 90% of participants with DPDR using a logistic regression - Emotional abuse significantly predicted diagnosis, and this increased when separation or loss was added to the regression

		● Pearson's correlations to explore the associations between different types of trauma	● Emotional abuse scores significantly predicted depersonalisation score on the DES ● Participants who experienced emotional abuse during childhood had a significantly earlier age of onset of DPDR ● Trauma was more severe for DPDR participants who had experienced emotional, physical and sexual abuse ● Emotional abuse was the most significant predictor of DPDR

Authors & Year of publication	Method	Analysis	Results
Simeon et al. (2008)	● Completed outcome measures for dissociation and childhood trauma	● Independent t-tests with Bonferroni correction	● Participants with DPDR had significantly higher total scores on the SDQ ● Emotional abuse was significantly correlated with higher depersonalisation scores on the CDS ● Somatoform dissociation was not related to any of the five types of trauma as measured by the CTQ-SF

Authors & Year of publication	Method	Analysis	Results
Simeon, Giesbrecht, et al. (2009)	● Participants were assessed by different diagnostic interviews ● Participants completed outcome measures for dissociation, depersonalisation and derealisation specifically, alexithymia, absorption, cognitive failures and childhood trauma	● Analysis of variance ● Binary logistic regression analyses ● Stepwise linear regression analyses	● The PTSD group had more experiences of childhood trauma than the DPDR group, except for emotional abuse and physical neglect ● The DPDR and PTSD group reported higher levels of emotional abuse than the control group but these scores did not show any significant difference between the DPDR and PTSD groups ● CTQ scores accurately predicted both PTSD and DPDR
Michal et al. (2016)	● Completed a psychometric assessment and clinical interview ● Clinical interview lasted at least 50 minutes and was	● Independent t-tests and Chi-square tests to compare groups ● Pearson correlations to investigate associations	● DPDR participants had similar levels of traumatic experiences in childhood to the depressed participants, but slightly fewer experiences of physical and sexual abuse ● The DPDR group showed no correlation between childhood trauma severity and depersonalisation severity

	delivered by a psychological professional ● Completed the Global Assessment of Functioning scale ● Completed outcome measures for depersonalisation and derealisation, depression, anxiety, social phobia, overall mental distress and childhood trauma	● Fisher r-to-z transformation to compare correlation coefficients between the two groups ● Logistic regression analysis and ANCOVA to control for differences observed between the groups ● Principal component analysis with varimax rotation to explore the distinctive symptom dimensions	● The DPDR group indicated lower rates of traumatic childhood experiences than the only depressed group

Eight (80%) of the studies indicated that there is an association between interpersonal abuse and DPDR. Correlations between overall CTQ scores and total CDS scores were found by Song et al. (2024), whilst moderate correlations between depersonalisation and derealisation scores and total CTQ scores were established for the dissociative disorder's participant group by Sar et al. (2017). Additionally, significantly higher levels of childhood interpersonal abuse experiences for DPDR participants compared with control groups were observed (Simeon et al., 1997; Simeon et al., 2001; Simeon et al., 2008; Simeon, Giesbrecht et al., 2009; Simeon & Knutselska, 2022). Moreover, Thomson & Jaque (2018) established that the DPDR group had experienced more adverse childhood experiences compared to the control group. These differences were significant for childhood abuse and childhood neglect (Thomson & Jaque, 2018). Nevertheless, Lee et al., (2012) did not evidence a relationship between DPDR and interpersonal abuse experiences. An explanation for this could be because they were looking at the association between interpersonal abuse and DPDR retrospectively and did not thoroughly assess experiences of DPDR using a reliable and valid outcome measure to detect depersonalisation and derealisation. Similarly, Michal et al. (2016) did not show an association between DPDR and interpersonal abuse experiences. However, they did find that between approximately 35% and 45% of the DPDR group reported clinically significant traumatisation following emotional abuse and emotional neglect, suggesting that this type of interpersonal abuse may still play a role in DPDR experiences.

Specifically, emotional abuse or emotional neglect were the type of interpersonal abuse most associated with DPDR. The DPDR participant group reported higher levels of emotional abuse or neglect in seven (70%) of the studies (Simeon et al., 2001; Simeon et al., 2008; Simeon, Giesbrecht et al., 2009; Michal et al., 2016; Thomson & Jaque., 2018; Simeon & Knutelska., 2022; Song et al., 2024). Simeon et al. (2001) and Simeon, Giesbrecht et al. (2009) established that DPDR participants had more experiences of emotional abuse than participants in the control group. Simeon and Knutelska (2022) discovered that emotional maltreatment was the only type of trauma which was significantly correlated with pathological dissociation for the DPDR participant group. Similarly, an earlier study by Simeon et al. (2008) showed that emotional abuse significantly predicted the severity of depersonalisation on the CDS. Moreover, Simeon et al. (2001) found that emotional abuse could significantly predict a DPDR diagnosis, in addition to the severity of the emotional abuse which also significantly predicted DPDR diagnosis. This prediction was even stronger when sexual abuse severity was added to emotional abuse severity in the regression analysis (Simeon et al., 2001).

Although there were six (60%) case-control studies which all found a relationship between interpersonal abuse and DPDR, a number of these studies were not specifically investigating this relationship. This meant that the studies were designed differently to observe relationships between clinical groups rather than healthy control groups. For example, two (20%) of the studies were designed to include extra groups of participants. One of these studies was Simeon, Giesbrecht et al. (2009) who investigated those with a diagnosis of PTSD without the dissociative subtype, in addition to participants with DPDR. This provided extra information such as the participants with PTSD evidencing significantly greater levels of childhood interpersonal abuse on the CTQ than the DPDR participant group, except for physical neglect and emotional abuse. Furthermore, apart from the category of emotional abuse, the DPDR group's reporting of childhood interpersonal abuse was similar to the control group, whereas participants with PTSD had more reported experiences of this. Consequently, results may be different when compared with other pathological groups rather than just healthy controls.

Apart from the study by Lee et al. (2012), all the papers identified included a comparison group in their design, although these were not always healthy control groups.

Furthermore, most of the studies used similar methods of analysis, including correlations, regressions and t-tests for investigating relationships between interpersonal abuse and DPDR and comparing scores between groups. This made the papers' results more easily comparable, despite the different study designs.

The study by Lee et al. (2012) did not evidence a relationship between interpersonal abuse and DPDR. This could be attributed to the design of the study, which was completely different from all other papers reviewed. Firstly, the participants were followed from birth and therefore were not selected for the purpose of the study. Participants with DPDR were identified via a present state examination at the age of 36 which included just two questions about depersonalisation and derealisation experiences. In comparison, participants in the other studies had their DPDR diagnosis confirmed via clinical interview such as the SCID-D and outcome measures for DPDR. Lee et al. (2012) explain that to meet the diagnostic criteria for DPDR, participants were required to score 'moderate' or 'intense' on the two questions about depersonalisation and derealisation. Only three participants scored 'intense' for depersonalisation or derealisation. A further 31 participants out of a possible sample of 3273, scored 'moderate' for questions on depersonalisation or derealisation or both. This provided a very small comparison sample in contrast with many of the other studies whose control groups were more equally balanced. Additionally, childhood trauma was recorded via information collated at datapoints in the first 24 years of life, whilst other research papers made use of trauma-related outcome measures. A benefit of these trauma-related outcome measures is that they explored levels of traumatisation whereas Lee et al's. (2012) study could only record incidences of abuse rather than measuring the impact of them. Hence, there were significant differences between the design and method of Lee et al's. (2012) study and the other studies systematically reviewed that may explain differences in the findings.

Quality Assessment

A quality assessment review found that all ten papers identified were good enough quality to include in the systematic review. Of these ten papers, three (30%) were considered to be of moderate quality, six (60%) were appraised as good quality and one (10%) was considered excellent quality (appendix B; appendix C). All papers appraised used standardised measures or method of assessment to identify DPDR. Reliable and valid outcome measures were also used to identify different types of trauma which meant that incidences of interpersonal abuse could be accurately measured. Quality was often reduced due to methodological issues with sample recruitment and size. Additionally, some papers did not provide details about the study participants and setting in detail.

Discussion

This systematic review investigated the relationship between interpersonal abuse and DPDR to discover if exposure to interpersonal abuse increases the risk of developing clinical DPDR. An initial 530 records were identified via systematic searching, of which 10 papers published between 1997 and 2024 were subsequently analysed, as per the quality assessment and inclusion criteria. Of these studies, 90% indicated that there is a relationship between experience of interpersonal abuse and DPDR. Specifically, emotional abuse and neglect was the most typical type of interpersonal abuse which demonstrated a relationship with clinical DPDR.

The finding that emotional abuse and neglect were the most common types of abuse linked with DPDR provides support for previous research which established a relationship between emotional abuse and neglect with depersonalisation and derealisation experiences and the dissociative subtype of PTSD (Michal et al., 2007; Gidzgier et al., 2019; King et al., 2020). It also confirms research by Laoide et al. (2017) who found that emotional maltreatment was a predictor for depersonalisation experiences. A possible reason for this link may be due to the association between emotional abuse and emotional neglect and the developing sense of self. For example, a study by Archuleta et al. (2024) explored the relationship between emotional maltreatment (comprising emotional neglect and emotional abuse) and social self-concept, which they defined as a person's perceived ability to form social relationships and connections. They found that experiences of childhood emotional maltreatment were related to poorer scores of social self-concept. Similarly, a meta-analysis by Zhang et al. (2023) established that emotional abuse and emotional neglect experienced during childhood were associated with reduced self-esteem following these experiences, both in childhood and adulthood. Research by Lassri et al. (2022) discovered that self-concept clarity was a protective factor in reducing depersonalisation and derealisation experiences for people who had experienced childhood sexual abuse. Consequently, if people with experiences of emotional abuse have reduced self-concept clarity or self-esteem, they may be missing a protective factor against depersonalisation and derealisation experiences, leading to more severe and chronic experiences of DPDR.

In addition to the relationship between emotional maltreatment and DPDR, the reviewed studies also provided evidence of the relationship between interpersonal abuse during childhood and a later diagnosis of DPDR. In fact, eight (80%) of the studies reviewed only investigated interpersonal abuse during childhood, neglecting to explore interpersonal abuse experiences during adulthood. It makes sense that the focus was on interpersonal abuse experiences during childhood as this is when they typically occur (Walby and Allen, 2004) However, the observed findings of a relationship between childhood interpersonal abuse and later clinical DPDR may not apply to interpersonal abuse experienced during adulthood. It is possible that emotional abuse and neglect experienced during childhood can affect the development of the self making a child vulnerable to developing clinical DPDR. An adult who experiences interpersonal abuse may already have developed a positive sense of self acting as a protective factor against DPDR. Therefore it may be that it is the time the abuse is experienced rather than the abuse itself that is associated with DPDR. Nevertheless, Thomson & Jaque (2018) did find that participants with DPDR had a greater amount of exposure to interpersonal trauma in both childhood and adulthood. Therefore, future research should focus on exploring if the relationship between interpersonal abuse and DPDR is maintained when this abuse is experienced during adulthood.

Strengths and Limitations of Studies

The majority of studies reviewed used accurate and similar outcome measures to assess experiences of interpersonal abuse. The Childhood Trauma Questionnaire (CTQ) or a variation of this, for example the Childhood Trauma Interview (CTI), was used to assess trauma in six (60%) of the studies. Although there are some limitations of the CTQ and CTI, such as a reliance on the accurate recall of traumatic experiences and no clear way of measuring the impact of these traumatic experiences (Karr et al., 2012), the CTQ and CTI have been demonstrated to be good measures for interpersonal abuse as it explores five different areas of trauma included in the interpersonal abuse definition (emotional abuse, physical abuse, sexual abuse, emotional neglect and physical neglect). The psychometric properties of the CTQ are good (Karr et al., 2012) whilst the CTI has shown positive convergence validity with the CTQ (Fink et al., 1995). Similarly, the Adverse Childhood Experiences (ACE) questionnaire used in the study by Thomson & Jaque (2018) has demonstrated positive convergent validity with the CTQ (Schmidt et al., 2020). Hence, even when different measures of trauma were used, these were still similar enough to accurately measure this phenomenon.

All the studies reviewed used valid and reliable outcome measures for depersonalisation and derealisation experiences. The most common of these was the Dissociative Experiences Scale (DES) or a variation of this which was utilised in seven (70%) of the studies reviewed. According to Simeon et al. (2001) the DES is the most typical measure for different dissociative experiences. The DES is comparable with other dissociative experience questionnaires and has demonstrated validity in predicting dissociative disorders (Van Ijzendoorn & Schuengel, 1996). The Cambridge Depersonalisation Scale (CDS) was also used in half the studies. The CDS has been shown to be an accurate measure to identify people who are likely to meet the clinical criteria for DPDR (Sierra & Berrios, 2000) and has shown good cross-cultural validity (Molina-Castillo et al., 2006; Sugiura et al., 2009; Kontoangelos et al., 2016). This is particularly important as the CDS was used in the reviewed studies with German and Chinese participants. Consequently, the use of valid and reliable measures across the studies, for measuring DPDR, helped to provide data which was deemed to be accurate and comparable.

In addition to valid and reliable outcome measures, over half the studies used the Structured Clinical Interview for DSM-IV Dissociative disorders (SCID-D) to confirm a clinical diagnosis of DPDR. The SCID-D interview was designed to provide clinical diagnoses for dissociative disorders based on the DSM diagnostic criteria (Mychailyszyn et al., 2020). The SCID-D is able to accurately differentiate individuals with dissociative disorders and without a dissociative disorder (Mychailyszyn et al., 2020). A meta-analysis by Mychailyszyn et al. (2020) evidenced that both depersonalisation and derealisation subscales of the SCID-D showed significant effect sizes for the ability to differentiate between those with and without dissociative disorders. Although the symptoms of depersonalisation and derealisation specifically did not differentiative dissociative disorder from other mental health disorders as successfully as all the dissociative symptoms together, the comparison effect sizes were still considered to be large when comparing dissociative disorders and non-dissociative disorders just by depersonalisation and derealisation symptoms (Mychailyszyn et al., 2020). Given the SCID-D is a reliable and valid measure, it provides support for the studies featured in this review as it is highly likely that participants with DPDR were given an accurate diagnosis of DPDR and hence were comparable for the purpose of this systematic review.

Some of the studies showed good clinical homogeneity. For example, the average age of participants with DPDR across the studies was over a 13 year span, ranging between participants in their early twenties and those in their mid-thirties. Furthermore, age of onset of DPDR was typically reported as 16 years old, providing support for other studies which have established this as a typical age for the onset of DPDR (Simeon et al., 2003). Hunter et al. (2017) report that individuals can wait for approximately seven to 12 years for a primary diagnosis of DPDR, which may explain why the average sample age across the studies was slightly older than the age of onset for DPDR.

In addition to clinical homogeneity, there was methodological homogeneity across some of the studies. For example, there were a number of case-control studies which had a healthy control comparison group. Participants were allocated to the DPDR group following a clinical interview, although this was not the case in every study. There was also a similarity in the way that participants were given outcome measures to complete and their subsequent results were compared with the control groups, with some shared methods of analysis, although this was not consistent across all studies. There were also some limitations regarding sample size and selection. Of the papers reviewed, only Song et al.'s. (2024) study conducted a statistical power calculation. Eight (80%) of the other studies did not show any consideration for how the sample size was determined. This is problematic as a sample size that is too small makes it challenging to reliably test a hypothesis, whilst a sample that is too large impacts on the time and resources spent on the study (Hajian-Tilaki, 2011). Meanwhile, Lee et al. (2012) did not have control over their participant selection due to the cross-sectional design, however, they recognised the lack of statistical power in their study. Overall, DPDR samples were small, averaging 50 participants. Kasiulevičius et al. (2006) affirm that a small sample size is acceptable when the population is homogeneous. To some extent, a homogenous population was chosen in many of the papers, as participants were grouped into those with a DPDR diagnosis. However, some studies involved participants who were recruited from the general population, for example, via a university. In these studies, participants were identified with a DPDR diagnosis following selection for the study. Hence, it is possible that some of these DPDR groups may have lacked homogeneity and a larger sample size may have been required to ensure validity of the study. Consequently, it is important to treat the findings of the studies with caution. Nevertheless, the overall findings consistently suggest a link between emotional maltreatment (comprising emotional abuse and emotional neglect) and DPDR which is considered to be reassuring despite the above concerns.

Strengths and Limitations of this Systematic Review

A systematic review pre-registration protocol was not completed. A systematic review pre-registration protocol helps to increase methodological rigour, supporting reviewers to effectively define the research question and develop an appropriate and focused search strategy, reducing the risk of bias. Engaging in protocol registration has been shown to significantly increase use of the PRISMA guidelines and the quality of the review (Van der Braak et al., 2022). Furthermore, pre-registration reduces the risk of duplicating others research. Nevertheless, despite the review not being pre-registered, the reviewer did conduct a search of existing pre-registered systematic reviews in the field of research, prior to engaging in the systematic review. Moreover, the review did follow clear guidelines for conducting a systematic review. Scoping searches were undertaken prior to the systematic search to establish the research already available, helping to determine the research focus and question. The relationship between interpersonal abuse and clinical DPDR was chosen due to an appraisal of the literature suggesting that this was an association that existed but had not been explored in a clinical population (Yang et al., 2023). Following the scoping searches, a clear search strategy was determined and followed, based on appropriate definitions for the phenomenon being studied.

The systematic review process was conducted by a single reviewer, including study selection and quality assessment. This may have resulted in a biased selection of studies, impacting the robustness of the systematic review. Tod et al. (2022) state that critical appraisal is a crucial part of systematic reviews. Critical appraisal involves identifying study type, establishing a suitable inclusion and exclusion criteria for study selection, selecting appropriate tools for assessing quality, conducting the appraisal and providing a summary of the results (Tod et al., 2022). Coder drift involves reviewers making decisions based on the inclusion/exclusion criteria that might differ from other reviewers (Polanin et al., 2019). Potential causes of coder drift are personal biases, fatigue or oversight, which could have all occurred during the review process. Having a single reviewer on this review meant that there were no other reviewers to identify any potential drift. Hence the inclusion/exclusion criteria may have been applied inconsistently and potentially useful and appropriate papers may have been excluded incorrectly. Gartlehner et al. (2020) found that when a single reviewer screened abstracts for a systematic review, they typically failed to identify 13% additional relevant studies. When a second reviewer was involved, the risk of missing appropriate studies reduced to just 3% (Gartlehner et al., 2020). Therefore, this single reviewer approach may mean that this review has "[lost] attributes of being systematic" (Puljak, 2017, p.4) and coder drift may have impacted the usefulness of the overall results due to potential missed studies.

Of the 10 papers included in the review, five (50%) had the same lead author. In addition, four (80%) of these papers had a further author in common. This helped to ensure some methodological homogeneity between these studies making them more comparable. For example, all five studies with the same lead author used the DES to measure experiences of depersonalisation and derealisation. However, having the same lead author and many of the same research team also presented the possibility that the results of the systematic review may be at risk of researcher bias. For example, the studies took place at the Mount Sinai School of Medicine and therefore may have recruited some of the sample participants. Therefore, the conclusions drawn from these studies should be treated with caution. However, whilst this may be a constraint, it also speaks to the limited amount of research studies that explore the relationship between interpersonal abuse and DPDR, indicating the importance of continued research in this area led by other research labs across the world.

Implications for Further Research and Clinical Practice

Despite some limitations, the majority of studies reviewed did evidence an association between interpersonal abuse and DPDR. However, most papers did not reflect on the influence of demographic factors, such as gender, age and ethnicity. Consequently, future studies may also wish to explore how these demographic factors may mediate the relationship between interpersonal abuse and DPDR.

Lee et al.'s (2012) study design was unique compared to the other studies in the review due to being longitudinal. This meant that they were not relying on participant's long-term recall. Furthermore, they were able to gather data about interpersonal abuse experienced by participants, prior to the onset of DPDR. Therefore, it may have presented a more accurate picture of the relationship between experiences of childhood interpersonal abuse and subsequent diagnoses of DPDR. Although Lee et al.'s (2012) findings were different to some of the other papers, it may be helpful to conduct further longitudinal studies to explore the replicability of these findings and minimise the risk of recall bias.

The review specifically focused on the relationship between people with a diagnosis of DPDR and interpersonal abuse. This presented a challenge during the systematic searches as studies about depersonalisation and derealisation experiences and people with other diagnoses such as the dissociative subtype of PTSD had to be filtered out. As a result, the reviewer was left with a limited amount of studies which investigated this direct relationship. Consequently, it may be difficult to draw conclusions about the relationship between interpersonal abuse and clinical DPDR from such a small sample of studies. Therefore, the reviewer recommends that future research studies should focus specifically on exploring experiences of depersonalisation and derealisation in a clinical population of people with DPDR.

The observed association between interpersonal abuse and DPDR is also an important consideration for clinical practice. Given that there is no clearly established diagnostic method to diagnose DPDR (Wilkhoo et al., 2024), this systematic review can help to guide clinicians in ensuring that they are exploring relevant factors in the development of DPDR. Additionally, highlighting the link between interpersonal abuse and DPDR can also help to inform appropriate clinical interventions for service users with this diagnosis. For example, trauma informed interventions and services that take into account this earlier interpersonal abuse may increase positive treatment outcomes. This is also an area that could subsequently be reviewed in future research studies.

Conclusion

Overall, this review indicates that there is a relationship between interpersonal abuse experiences and DPDR. When explored further, it appears that emotional maltreatment is the most typical type of abuse to evidence this relationship. Furthermore, the interpersonal abuse experiences typically occur during childhood, although this may be because research is limited in regards to the association with interpersonal abuse experienced during adulthood. The studies reviewed showed some homogeneity clinically and methodologically, but this was not the case across all the studies. Moreover, the results may have been affected by researcher bias and challenges also existed with the review method itself. Consequently, further research should specifically consider two factors in the etiology of DPDR, namely: emotional maltreatment and the effect of adult interpersonal abuse. Furthermore, the limited amount of studies available to review, evidence the importance of a greater emphasis on research into DPDR in a more geographically inclusive manner, to improve diagnosis and treatment outcomes for those with DPDR experiences.

Chapter 2

Chapter Overview

The following chapter outlines the quantitative study. Relevant research is explored and appraised in the introduction. The methodology section follows, explaining the aims of the research and reasons for choosing these. The researcher's epistemological position is discussed and the influence of this on the study and methods chosen are appraised. The methodology for the quantitative study is outlined, highlighting design, setting, sample, materials, variables, procedure, data analysis, and ethical considerations. Trustworthiness of the overall study is considered. The results section reports the findings of the quantitative study. Results are then interpreted and explored further in the discussion section. This section also makes recommendations for future clinical practice when working with DPDR and potential research areas for exploration.

Introduction

Adverse Childhood Experiences and dissociation

The systematic review highlighted that much of the research into the relationship between interpersonal abuse and DPDR was focused on experiences of childhood interpersonal abuse. Given that an association between these experiences was observed, it also suggests that adverse childhood experiences may play a causal role in DPDR. Adverse childhood experiences are defined as "stressful or traumatic events that disrupt the child development process" (Yoon et al., 2023, p.280). In addition to interpersonal abuse, adverse childhood experiences include living with caregivers with a substance or alcohol addiction, having a family member in prison, living with a family member who has a mental illness and experience of parental divorce or abandonment (Center for Disease Control and Prevention [CDC], 2024).

Research has shown that children who have these adverse experiences are more likely to have poorer health outcomes later in life (Chang et al., 2019; Webster, 2022). For example, a study by Felitti et al. (1998) found that the amount of exposure to abuse and dysfunctional situations in the home were risk factors in causes of adult deaths. Similarly, research has evidenced that in addition to poorer physical health outcomes, adverse childhood experiences were also related to increased mental health difficulties and difficulties making and maintaining social relationships (Kendall-Tackett, 2002; Chang et al., 2019; Webster, 2022). Furthermore, a systematic review by Haczkewicz et al. (2024) found that individuals who are exposed to adverse childhood experiences are more likely to have a diagnosis of two or more chronic illnesses, experience problems with their cognitive functioning, experience symptoms of depression and struggle with their social wellbeing compared with their peers who have had no experience of childhood adversity.

Quiñones (2022) states that two factors are important to understand the relationship between adverse childhood experiences and pathological dissociation. These factors are as follows:

> 1) how traumatic and developmental stress from exposure to [adverse childhood experiences] disrupt and impede developmental capacities that give rise to trauma-related and dissociative symptomology and disorders, and 2) what factors support a pathway between adverse childhood experiences-related distress, disruptions in beneficial development, and experiential disconnection from distress-related dissociation, and pathological forms of dissociation during development. (Quiñones, 2022, p.213)

To answer this, Quiñones (2022) identifies three elements which help to explain the relationship between adverse childhood experiences and dissociation. These elements are related to a person’s formative attachment experiences, how the person perceives the threat related to the traumatic experience and how this affects overall functioning. Quiñones (2022) continues that it is the distress caused by adverse childhood experiences that disrupts these three elements leading to dissociative experiences. Furthermore, having multiple adverse childhood experiences leads to heightened distress and augmented disconnection from the world, which subsequently increases susceptibility to these elements and greater risk of dissociation (Quiñones, 2022).

In addition to dissociative experiences, there is evidence that DPDR has a relationship with direct adverse childhood experiences (abuse and neglect), as already described in the systematic review. However, studies are sparse on the relationship between indirect adverse childhood experiences (living with caregivers with a substance or alcohol addiction, having a family member in prison, living with a family member who has a mental illness and experience of parental divorce or abandonment) and DPDR. Quiñones (2022) suggests that indirect adverse childhood experiences can lead to household dysfunction which subsequently increases the risk of trauma and dissociative responses. Lander et al. (2013) explored the effect of parental substance use disorders on children and proposed that parents with a substance use disorder are likely to experience dysregulated mood, making it difficult to regulate and contain their own children’s emotions, an important aspect of secure attachment. Quiñones (2022) highlights that a lack of a secure attachment is one of the key factors in the pathway to pathological dissociation. Consequently, it is possible that indirect adverse childhood experiences are likely to be associated with dissociative experiences which include depersonalisation and derealisation, due to increased household dysfunction and insecure attachment styles; namely anxious, avoidant and disorganised.

Additionally, another hypothesis for a potential relationship between adverse childhood experiences and dissociation, namely depersonalisation and derealisation is the stigma related to the trauma. A study by Lashkay et al. (2023) investigated the relationships between adverse childhood experiences, disidentification and dissociation. Lashkay et al. (2023) found that when trauma was perceived as greatly stigmatising, participants were significantly more disidentified from the traumatic incident, increasing the dissociative experiences, as measured by the depersonalisation/derealisation subscale from the Dissociative Subtype of PTSD Scale (Wolf et al., 2017). Therefore, the perceived stigmatisation of the trauma related to the adverse childhood experience may be a mediating factor in its association with dissociative experiences such as depersonalisation and derealisation. Hence, this is worth further exploration.

Individualism and depersonalisation/derealisation

In addition to a potential relationship between adverse childhood experiences and depersonalisation and derealisation experiences, a possible moderating factor with depersonalisation, is the sense of individualism that an individual experiences. Individualism is a concept often influenced by society and culture that highlights an individual’s uniqueness, valuableness and their right to autonomy (APA, n.d.). A systematic review by Sierra-Siegert and David (2007) explored the relationship between depersonalisation and derealisation experiences during panic attacks for people with panic disorder diagnoses. They found that individuals from a western culture had a greater frequency of depersonalisation experiences and higher individualism scores across multiple studies (Sierra-Siegert & David, 2007). This suggested that individuals from a Western culture were more likely to have a greater sense of individualism, possibly increasing their risk of experiencing depersonalisation and derealisation during panic attacks.

Religion and depersonalisation/derealisation

Cohen and Hill (2007) argue that religion is also associated with an individual’s degree of individualism. They propose that religions which emphasise spiritual processes between the individual and God and focus on personal faith, are more likely to be individualist in nature (Cohen & Hill, 2007). Alternatively, religions which emphasise social relationships and community are more likely to be less individualistic (Cohen & Hill, 2007), such as Judaism or Hinduism. This infers that similarly to the impact of culture on individualism as suggested by Sierra-Siegert & David (2007), membership of a religious group or religious experiences may also influence levels of individualism and subsequent depersonalisation and derealisation experiences. Therefore, it is important to further explore how religion may also be related to depersonalisation and derealisation experiences.

Studies have already shown a relationship between religion and dissociative experiences. Maraldi (2024) claims that spiritual and religious experiences can be dissociative in nature, hence people might be more susceptible to dissociation due to these experiences. A study by Dorahy and Lewis (2001) investigated the relationship between religion and dissociation in Catholic, Christian and student participants. They found that scores on dissociation measures were greatest for the young catholic group but second greatest was the non-religious student group (Dorahy & Lewis, 2001). They suggest that age may be a confounding variable in their study, however still hypothesise that religion may be a protective factor against dissociative experiences. Another study by Breslin and Lewis (2015) investigated the predictive relationship of dissociation on religious experiences and found that a combination of dissociation and prayer was significantly predictive of religious experience. Despite these findings which suggest that there is a relationship between dissociation and religious or spiritual experiences, there appears to be few research studies which have specifically looked at the association between religious and spiritual experiences with DPDR.

A scoping review by Diego-Cordero et al. (2022) did find that nurses who engaged with spiritual and religious beliefs were less likely to have burnout and experience depersonalisation. This suggests that whilst religion might be responsible for increased dissociative experiences, it can also play a role as a protective factor against DPDR.

Gender and depersonalisation/derealisation

Gender is another interesting factor in the expression of DPDR. As already noted, Wilkhoo et al. (2024) affirms that DPDR affects equal amounts of males and females. This has not always been the case as Schlozman and Nonacs (2008) stated that women experience depersonalisation disorder at twice the rate of men. More recently, Fritscher (2023) suggests that women are more likely to have experiences of depersonalisation and derealisation than their male counterparts. Moreover, some studies into DPDR have a female majority sample, whilst others have a male majority, as seen in the systematic review. Consequently, further exploration of gender is required. Furthermore, research also suggests that individuals with gender dysphoria are 30% more likely to have a diagnosis of a dissociative disorder and 45.8% more likely to have had an adverse childhood experience (Colizzi et al., 2015). The DSM-5 (APA, 2013) states that "gender dysphoria refers to the distress that may accompany the incongruence between one's experienced or expressed gender and one's assigned gender." (p.451). Research has evidenced that depersonalisation experiences are significantly increased in transgender people who have not undergone gender reassignment surgery (Walling et al., 1998; Kersting et al., 2003; Bandini et al., 2013; Fisher et al., 2014). Jones (2018) suggests that depersonalisation experiences occur when gender dysphoria is untreated and is therefore a common experience. Hence, it is also important to explore the prevalence rate of DPDR in individuals who identify as transgender or non-binary.

Self-concept clarity and depersonalisation/derealisation

Self-concept clarity is another important factor to understand in the relationship between adverse childhood experiences and DPDR. A study by Wong et al. (2019) found that self-concept clarity was a mediating factor for depression, suicidality, stress and loneliness in participants who had adverse childhood experiences. They also found that participants with multiple adverse childhood experiences had a lower self-concept clarity score. Consequently, a lower self-concept clarity score was associated with poorer mental health outcomes. Similarly, a study by Morstead and DeLongis (2023) found that participants with more adverse childhood experiences had lower scores on a measure for self-concept clarity. Meanwhile, Evans et al. (2015) showed that self-concept clarity was a mediating factor between adverse childhood experiences and psychosis. Moreover, they also discovered a significant correlation between self-concept clarity and dissociative experiences (Evans et al., 2015). Building on this, further studies have investigated the relationship between self-concept clarity, adverse childhood experiences and dissociation. For example, Paetzold and Rholes (2021) found that participants who had disorganised attachment patterns with abuse experiences during childhood, also showed higher levels of dissociation and reduced levels of self-concept clarity. Likewise, Lassri et al. (2022) investigated the relationship between childhood sexual abuse, self-concept clarity and dissociative experiences, specifically depersonalisation and derealisation. They found that individuals who had experienced sexual abuse during childhood had increased experiences of depersonalisation and derealisation, but this effect was mediated by self-concept clarity. Consequently, whilst a relationship between adverse childhood experiences and DPDR does appear to exist, this suggests that a sense of self-concept is an important mediating factor. Furthermore, the research indicates that exposure to adverse childhood experiences can reduce an individual’s sense of self. As a lower sense of self-concept is also related to increased depersonalisation and derealisation experiences, it therefore makes sense that individuals with exposure to adverse childhood experiences are likely to be more vulnerable to depersonalisation and derealisation experiences.

Other moderating factors

In sum, there appears to be strong evidence for a relationship between adverse childhood experiences and both depersonalisation and derealisation experiences as well as clinical DPDR. However, this association may be mediated by factors such as self-concept clarity, attachment style, gender or gender dysphoria and religion or spirituality. Therefore this study was designed to explore the relationship between adverse childhood experiences and experiences of depersonalisation and derealisation whilst taking into account the mediating effects of gender and religion as well as self-concept clarity. The study intended to answer the research questions outlined in Chapter 1, related to the relationship between adverse childhood experiences and depersonalisation and derealisation and the role of religion, gender and self-concept clarity in depersonalisation and derealisation experiences.

Methodology

Research Aims

This study aimed to investigate whether traumatic events experienced during childhood predicted experiences of depersonalisation and derealisation in adulthood. The researcher was also interested in exploring the effect of gender and religion on any observed associations between adverse childhood experiences and depersonalisation and derealisation. Additionally, this study hoped to support earlier research by Lassri et al. (2022) that self-concept clarity plays a role in mediating the effects of depersonalisation and derealisation. The study also aimed to explore whether a potential relationship with childhood trauma is unique to depersonalisation and derealisation or if it is present in anxiety and depression. The researcher hypothesised the following:

1) There would be a significant positive relationship between experiences of childhood trauma and experiences of DPDR, depression, generalised anxiety and a felt sense of anomaly.
2) There would be a significant negative relationship between perception of self-concept clarity and experiences of DPDR, depression, generalised anxiety and a felt sense of anomaly.
3) There would be a significant effect of religion and gender on experiences of DPDR.
4) Religion, gender and self-concept clarity would be mediating factors between abuse experienced during childhood and experiences of DPDR

The research paradigm

A research paradigm determines the philosophical position that underpins how research is carried out and how any subsequent results are understood (Finn et al., 2022). Thinking about the research paradigm ensures the quality of the research and helps the researcher to think about how this aligns with the aims of the study (Finn et al., 2022). There are four philosophical aspects which comprise a research paradigm. These are ontology, epistemology, axiology and methodology (Alele & Malau-Aduli, 2023). Axiology is concerned with the value of the research, ontology is concerned with how reality is perceived and determined, epistemology considers knowledge and methodology is the strategy that informs the research design (Alele & Malau-Aduli, 2023). Each element of the research paradigm in this study is considered below.

Ontology

Ontology helps the researcher to conceptualise their understanding (Alele & Malau-Aduli, 2023). Two key ontological stances are positivism and constructionism. Positivism assumes that the world contains real objects and rules and things are explained by observed patterns (Fryer & Navarrete, 2024). Meanwhile constructionism holds a sceptical point of view, focusing on meaning making from language and other qualitative sources (Fryer & Navarrete, 2024). Neither of these stances captured the ontological approach to the study. Instead, Fryer & Navarrete (2024) propose a third stance of realism. Fryer & Navarrete (2024) affirm that a realist position focuses on "the way human action is influenced by our psychological life, the meaning we give things, the physical environment in which we happen to be, and the relations within and between these three things" (p.26). The realism approach offers a middle ground between a positivist and constructionist position and was more appropriate and relevant to this study because it acknowledged the reality of DPDR whilst also recognising that the experience may be influenced by socially constructed factors. In particular, the quantitative component of this study adopted a critical realist position. Critical realism proposes that reality is separate from human consciousness (Smith, 2010) and is influenced by theory. Critical realism not only thinks about the relationship between events and the way they are experienced but also considers the underpinning factors which may be affecting the relationship (Fryer & Navarrete, 2024). In the context of this study, psychometric outcome measures were used to measure experiences of psychological phenomena. However, holding this ontological position allowed the researcher to be critical of the observing findings and recognise the limitations of the tools. In doing so, the researcher was able to explore other ideas that were contributing to the observed findings.

Epistemological Positioning

“Epistemology is a branch of philosophy that concerns itself with the theory of knowledge” (Sol & Heng, 2022, p.80). Brown (2015) explains that epistemology in research is concerned with how knowledge is obtained based on the researcher’s own interpretation of the world. In alignment with the ontological positioning, this quantitative study adopted a post-positivist epistemological position. A post-positivist stance proposes that the researcher themself affects what is measured, observed and concluded in the study and therefore acknowledges the potential bias in the data collected (E-International Relations, 2021). A post-positivist position was appropriate for this study because the researcher used structured and empirically based measures to explore a complex phenomenon (DPDR) but acknowledged the limitations of these measures in fully assessing all the complexities of DPDR.

Axiological Positioning

According to Alele & Malau-Aduli (2023), axiology helps the researcher to think about their values, role and influence on the study and how this impacts their attempt to gain knowledge about the phenomenon they are researching. They suggest that the researcher thinks about the following areas when examining their axiological position: how to respect participants, ethical principles, cultural considerations and how to limit risk issues that may arise during the study (Alele & Malau-Aduli, 2023). I considered this in both the quantitative and qualitative components of the overall study.

I am a 32-year-old heterosexual female who identifies as being from a white other ethnic background. I am also Jewish and religious. This position influenced the aims of the quantitative study. I was interested in investigating whether particular demographic factors mediated the relationship between aetiological factors in DPDR and DPDR experiences. My positioning helped me to consider the role of religion as a possible mediating factor. Religion or spiritual beliefs has been found to be a protective factor in other mental health difficulties and against other dissociative experiences (Diego-Cordero et al., 2022). However, little was known about religious or spiritual experiences in relation to DPDR so I hoped to bring a new perspective to this field of research.

Study design

Design

This is a mixed methods study with a quantitative component employing an exploratory survey design and a qualitative component employing an interview design. The quantitative component is discussed here whilst the qualitative component will be discussed in Chapter 3. The survey utilised a cross-sectional design, gathering data from those with depersonalisation and derealisation experiences as well as the general population at one point in time. A quantitative component was chosen to empirically explore possible aetiological and maintaining factors of DPDR. Participants were asked to complete an online survey which comprised several validated and reliable questionnaires, in addition to a set of demographic questions. Utilising a survey and completing this online meant that the researcher could collect data speedily and effectively from a large group of participants (Jones et al., 2013), including those from the DPDR community.

Setting

The survey was conducted online via Qualtrics and participants completed this remotely from wherever they felt most comfortable. Participants were able to use any device that had the capacity to access the survey online.

Sample

The second part of this study recruited individuals aged 18 or over to complete a questionnaire on their current mental health experiences including depersonalisation-derealisation symptoms, their past life experiences and relationships with others. A purposeful sampling method was used to recruit the participants. The questionnaire was published via the University of Essex, on SONA and on Prolific. The charity UNREAL was also contacted and the questionnaire was advertised on their website.

A G*Power analysis was conducted to indicate the appropriate sample size for this study to attain a 0.95 power at an alpha level of 0.05 in order to detect a medium effect size of 0.3 for a one-tailed test. A one-tailed test was selected as numerous previous studies have indicated a positive relationship between exposure to childhood trauma and experiences of depersonalisation and derealisation, so it was appropriate to assume a directional hypothesis. A medium effect size was selected based on four previous studies investigating the relationship between childhood trauma and experiences of depersonalisation and derealisation, which had used similar predictors and outcome measures to the current study. Simeon et al. (2008) discovered a significant correlation between emotional abuse and total scores on the CDS, with a medium effect size of 0.33. Meanwhile King et al. (2020) established a small to medium 0.2 effect size for a significant correlation between emotional abuse and depersonalisation and derealisation as measured by the Dissociative Subtype of PTSD Scale. The final two studies by Paetzold and Rholes (2021) and Lassri et al. (2022) also investigated self-concept clarity as a mediating factor. Paetzold and Rholes (2021) looked at dissociative experiences rather than depersonalisation and derealisation specifically but found a large effect size of 0.563 for the correlation between child abuse and dissociation and a large effect size of 0.525[1] for the

---

[1] Paetzold and Rholes (2021) observed a large positive effect size rather than negative effect size. This was because they reported that larger values on the measure of self-concept clarity indicated less clarity. Therefore having less clarity about the self showed a pattern of greater dissociation for given values of disorganised attachment.

correlation between self-concept clarity and dissociation. A medium to large effect size of 0.459 also existed for the correlation between childhood abuse and self-concept clarity. Meanwhile, Lassri et al. (2022) found a large effect size of 0.523 for the correlation between childhood sexual abuse and depersonalisation and derealisation and a large negative effect size of -0.511 for the correlation between self-concept clarity and depersonalisation and derealisation. A medium negative effect size of -0.321 also existed for the correlation between childhood sexual abuse and self-concept clarity. Given this range of effect sizes between 0.2 and 0.5 it was appropriate to assume a medium effect size of 0.3 for our sample size calculation. The G*Power analysis indicated a minimum required sample size of 111 participants. To account for drop-out rates and any outliers, the researcher intended to recruit a minimum sample of 123.

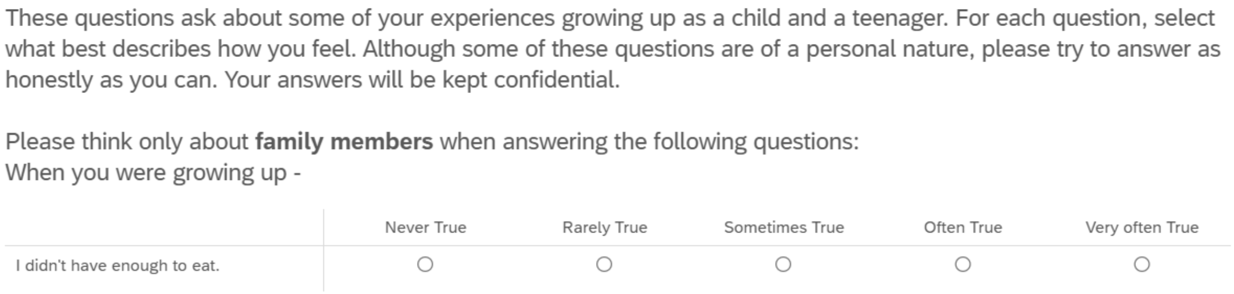
Materials

The researcher used Qualtrics to distribute the online questionnaire to participants. The questionnaire given to participants included the Childhood Trauma Questionnaire Short Form (CTQ-SF; Bernstein et al., 2003), the PTSD Checklist for DSM-5 (PCL-5; Weathers et al., 2013), the Life Events Checklist for DSM-5 (LEC-5; Weathers et al., 2013), the Felt Sense of Anomaly (FSA; Černis et al., 2021), the Cambridge Depersonalisation Scale (CDS; Sierra & Berrios; 2000), the Patient Health Questionnaire-8 (PHQ-8; Kroenke et al., 2009), the Generalised Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006) and Self-Concept Clarity (SCC; Campbell et al., 1996) questionnaire. Additionally, the Revised Adult Attachment Scale (Collins, 1996) was provided although this was for use in a separate study and results were not analysed for the purpose of this study. The CTQ-SF was adapted to consider both familial and non-familial (nf) experiences of abuse (appendix D).

The CTQ (Bernstein et al., 1994) is a widely recognised assessment tool for childhood abuse and neglect in the international community (Grassi-Oliveira et al., 2014). The CTQ-SF is a briefer form of this questionnaire which was developed to take a maximum of five minutes to complete (Bernstein et al., 2003). The CTQ-SF consists of 28 items, three of which pertain to items concerning minimisation/denial and 25 of which pertain to clinical items (Bernstein et al., 2003). The 25 clinical items include five subscales (emotional neglect, physical neglect, emotional abuse, physical abuse and sexual abuse) each consisting of five items (The Human Condition Editorial Team, 2022). Participants were asked to choose a rating on a five-point Likert scale (1 = Never True, 2 = Rarely True, 3 = Sometimes True , 4 = Often True , 5 = Very Often True) based on how best the item described the way they felt (Figure 2.1). Seven items were positively worded and therefore their scoring was reversed. Each subscale was summed providing a score between five and 25 and a total clinical score of 125. Higher scores on the CTQ-SF indicated a greater degree of childhood maltreatment. For the purpose of this study, two similar versions of the CTQ-SF were utilised, one which asked participants to think about experiences in a familial context (all 25 original items) and another which asked participants to think about experiences in a non-familial context (18 of the original items, reworded where appropriate, e.g. “There was someone in my family who helped me feel important or special” was replaced with “There was someone who helped me feel important and special.”).

Figure 2.1

Example of the Childhood Trauma Questionnaire Short Form (CTQ-SF) for familial abuse



These questions ask about some of your experiences growing up as a child and a teenager. For each question, select what best describes how you feel. Although some of these questions are of a personal nature, please try to answer as honestly as you can. Your answers will be kept confidential.

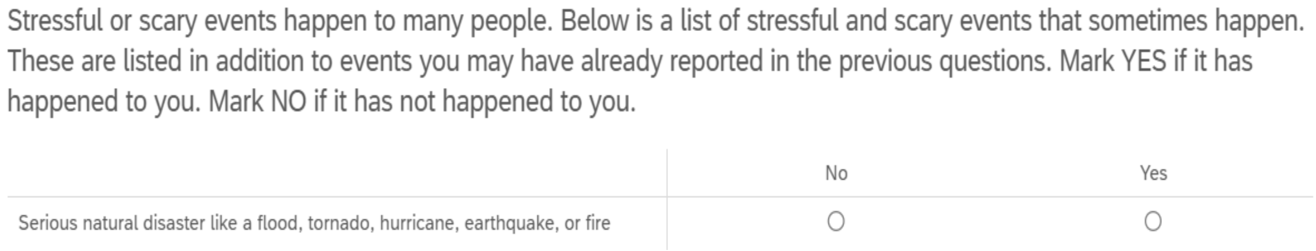
Please think only about **family members** when answering the following questions:
When you were growing up -

	Never True	Rarely True	Sometimes True	Often True	Very often True
I didn't have enough to eat.	○	○	○	○	○

The PCL-5 (Weathers et al., 2013) was designed to assess individuals for PTSD and observe changes during therapeutic treatment for PTSD (International Society for Traumatic Stress Studies, 2024). Blevins et al. (2015) investigated the reliability and validity of the PCL-5 in two studies. They found that the PCL-5 had excellent reliability and validity and affirmed that the measure accurately assesses PTSD symptoms (Blevins et al., 2015). Similarly to the PCL-5, the LEC-5 (Weathers et al., 2013) was established to assess experience of traumatic events and support PTSD diagnoses (NovoPsych, 2025). It also demonstrated good reliability and validity, accurately measuring psychological distress and PTSD (Gray et al., 2004; Stevenson et al., 2023). The PCL-5 with LEC-5 was presented in two parts. Part one consisted of the LEC-5 although this was adapted from its original form for the purposes of the survey. Participants were asked about eight different stressful or scary events and were required to select yes or no depending on whether the experience had happened to the participant (Figure 2.2). Part two consisted of the PCL-5 where participants were asked to think about their stressful or scary experiences and rate how much they were bothered by 20 different symptoms of PTSD in the last two weeks (Figure 2.3). Participants rated this on a four-point Likert scale (0 = never, 1 = once in a while, 2 = Half the time, 3 = Almost always). The National Center for PTSD (2025b) advises that the PCL-5 severity scores are summed to create a total score between zero and 80. The clinical cutoff score is between 31 to 33 so any scores above this were considered indicative of PTSD (The National Center for PTSD, 2025b). The LEC-5 was not scored as this measure aims to assess exposure to traumatic events but is not a quantitative measure (The National Center for PTSD, 2025c).

Figure 2.2

Example of the Life events Checklist for DSM-5 (LEC-5) Part 1

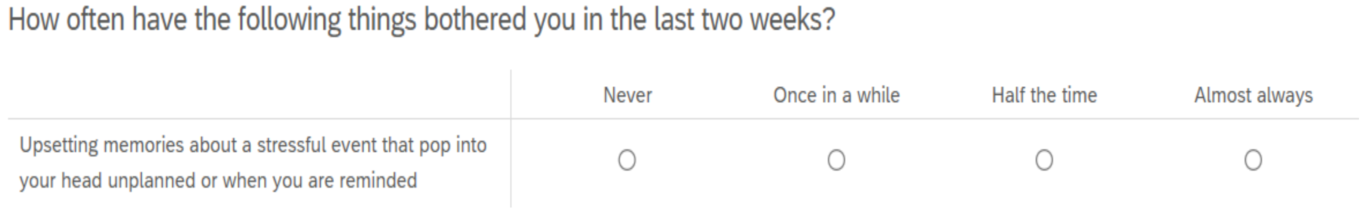


Stressful or scary events happen to many people. Below is a list of stressful and scary events that sometimes happen. These are listed in addition to events you may have already reported in the previous questions. Mark YES if it has happened to you. Mark NO if it has not happened to you.

	No	Yes
Serious natural disaster like a flood, tornado, hurricane, earthquake, or fire	○	○

Figure 2.3

Example of the PTSD Checklist for DSM-5 (PCL-5) Part 2



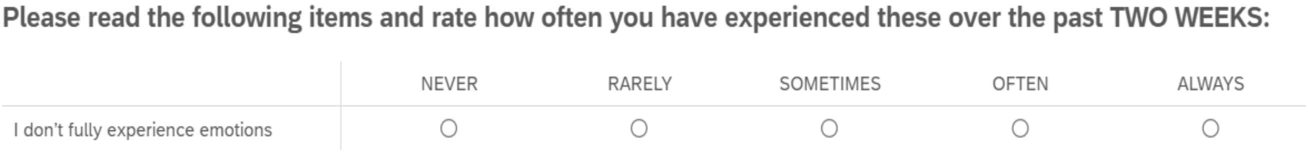
How often have the following things bothered you in the last two weeks?

	Never	Once in a while	Half the time	Almost always
Upsetting memories about a stressful event that pop into your head unplanned or when you are reminded	○	○	○	○

The FSA was designed to measure a specific subset of dissociative symptoms (Černis et al., 2021). Černis et al. (2021) discovered that a felt sense of anomaly is a typical experience in dissociation that significantly affects everyday functioning. The outcome measure was used in a large group of people with psychosis and was found to reliably and accurately measure the felt sense of anomaly experience present in dissociation (Černis et al., 2021). A translated version in German replicated these findings, indicating that the measure was both reliable and valid (Heekerens et al., 2025). In this study the short-form FSA (Černis et al., 2024) was presented to participants. The short-form FSA was a valid and reliable measure of the felt sense of anomaly experience in dissociation, for both clinical and non-clinical participants in the study (Černis et al., 2024). Černis et al. (2024) recommend that this measure is used to explore dissociative experiences prior to any other dissociative outcome measures. The short-form FSA consisted of 14 items which asked participants about different aspects contributing to felt sense of anomaly which they had experienced over the previous two weeks (Figure 2.4). Participants were required to rate the frequency of their symptoms on a five-point Likert scale (0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = always). The FSA consists of seven subscales: anomalous experience of the self, anomalous experience of the body, anomalous experience of emotion, altered sense of familiarity, altered sense of connection, altered sense of agency and altered sense of reality (Černis et al., 2024; Heekerens et al., 2025). Černis et al. (2024) affirmed that it is useful to find the total score on the short-form FSA. A maximum total score of 56 could be achieved on the short-form FSA (Černis et al., 2024). Participant scores between 0 and 28 were considered as average FSA dissociation, a score between 29 and 38 was determined as elevated FSA dissociation, moderately severe FSA dissociation was between 39 and 48 and severe FSA dissociation was a score between 49 and 56 (Černis et al., 2024).

Figure 2.4

Example of the Felt Sense of Anomaly (FSA)



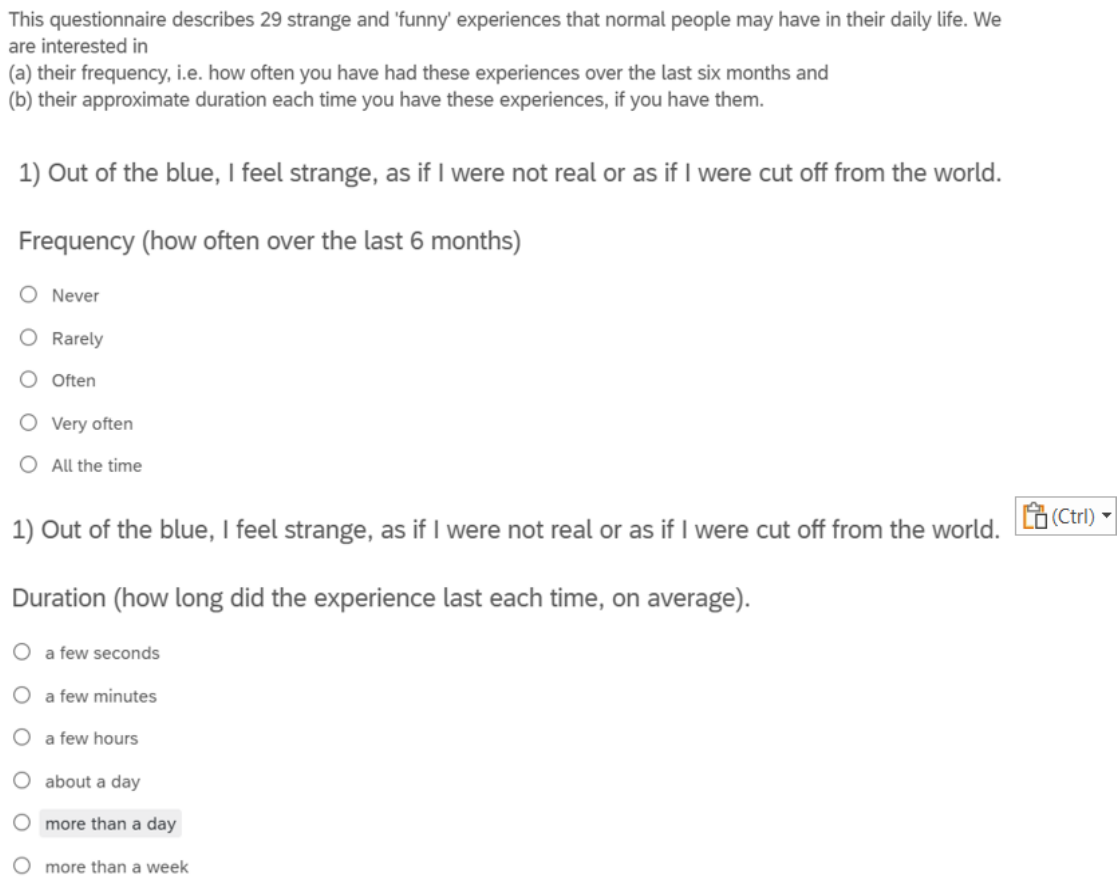
Please read the following items and rate how often you have experienced these over the past TWO WEEKS:

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
I don't fully experience emotions	○	○	○	○	○

The CDS was developed in response to prior assessment tools for depersonalisation which had shown poor validity (Sierra & Berrios, 2000). The assessment tool indicated excellent internal consistency and reliability and is therefore a valid and reliable measure to assess experiences of depersonalisation (Sierra & Berrios, 2000). The CDS consisted of 29 items which asked participants about their experiences of depersonalisation over the last six months (Figure 2.5). Participants were asked to rate the frequency of their symptoms on a five-point Likert scale (0 = never, 1 = rarely, 2 = often, 3 = very often, 4 = all the time) and the duration of their symptoms on a six point Likert scale (1 = few seconds, 2 = few minutes, 3 = few hours, 4 = about a day, 5 = more than a day, 6 = more than a week). The CDS comprises four subscales: Anomalous Body Experience (nine items), Emotional Numbing (six items), Alienation from Surroundings (four items) and Anomalous Subjective Recall (five items; Frewen et al., 2015). A total score for the questionnaire was calculated and any score above 70 indicated clinically significant experiences of depersonalisation (Sedeño et al., 2014).

Figure 2.5

Example of the Cambridge Depersonalisation Scale (CDS)



This questionnaire describes 29 strange and 'funny' experiences that normal people may have in their daily life. We are interested in
(a) their frequency, i.e. how often you have had these experiences over the last six months and
(b) their approximate duration each time you have these experiences, if you have them.

1) Out of the blue, I feel strange, as if I were not real or as if I were cut off from the world.

Frequency (how often over the last 6 months)

○ Never
○ Rarely
○ Often
○ Very often
○ All the time

1) Out of the blue, I feel strange, as if I were not real or as if I were cut off from the world.

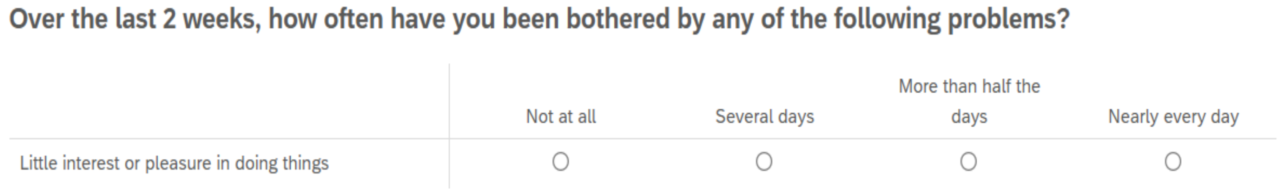
Duration (how long did the experience last each time, on average).

○ a few seconds
○ a few minutes
○ a few hours
○ about a day
○ more than a day
○ more than a week

The PHQ-8 (Kroenke et al., 2009) is a shorter and quicker version of the PHQ which can be self-administered to detect the possibility of depression (Marvin, 2011). The PHQ-8 is an equivalent version of the PHQ-9 (Kroenke et al., 2001), excepting the item “thoughts of death or suicide” which is removed in the PHQ-8 (Corson et al., 2004). The PHQ-8 typically comprises eight statements which respondents are asked to rate on a four-point Likert scale (0=not at all, 1=several days, 2=more than half the days, 3=nearly every day; Figure 2.6). A maximum score of 24 can be achieved on the PHQ-8 (Kroenke et al., 2009). A total score above 20 indicated severe depression (Marvin, 2011). A score between 15 and 19 suggested moderately severe depression and moderate depression was indicated by a score between 10 to 14 (Kroenke et al., 2001; Kroenke et al., 2009; Marvin, 2011). Kroenke et al. (2001) evidenced that internal reliability and test-retest reliability for the PHQ-9 was good. The PHQ-9 also demonstrated high accuracy for diagnosing depression and measuring its severity (Kroenke et al., 2001). The PHQ-9 has been demonstrated to be an excellent measure of depression amongst a diverse range of populations including ethnic groups, older adults and pregnant or postpartum women (Kroenke, 2021). The equivalent PHQ-8 has also shown a high sensitivity and specificity. In a sample of 198, 678 participants, Kroenke et al., (2009) found that 100% (8476) of major depression cases were accurately diagnosed with a score above the clinical cut-off of 10 whilst other types of depression or no depressive disorder were accurately identified in 95% (181,638) of the cases. Whilst the PHQ-9 is an excellent measure, item number 9 which asks about self-harm and suicidality has been considered to be problematic as a full mental health assessment and access to appropriate support cannot necessarily be provided when asking the question to a large population (Shin et al., 2019), as in the current study. Consequently, as the PHQ-8 is an equivalent measure of the PHQ-9 which has also shown to be reliable and valid, it was selected for the current study to recognise depression but avoid the potential of raising any clinical risks.

Figure 2.6

Example of the Patient Health Questionnaire-8 (PHQ-8)



Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	○	○	○	○

The GAD-7 (Spitzer et al., 2006) was presented alongside the PHQ-8 in this study. It is measured on the same four-point Likert scale (0=not at all, 1=several days, 2=more than half the days, 3=nearly every day) as the PHQ-8, with the main difference being that the statements pertain to anxiety rather than low mood (Figure 2.7). The clinical cut off points for mild, moderate and severe anxiety were a score above 5, 10, or 15 (Spitzer et al., 2006). A total score of 21 could be achieved. The greater the score, the greater level of anxiety experienced. The GAD-7 was developed as a measure to facilitate a straightforward way of assessing generalised anxiety disorder, as no such measure had previously existed (Spitzer et al., 2006). The reliability and validity of the GAD-7 in assessing generalised anxiety was strong when used in clinical practice and research (Spitzer et al., 2006). It has continued to show excellent accuracy and consistency as an outcome measure, amongst other ethnic populations such as Kinyarwanda speaking people and Latin Americans (Mūller et al., 2024; Moreno-Montero et al., 2025). It was therefore an appropriate measure to assess the anxiety levels of the participants in this study.

Figure 2.7

Example of the Generalised Anxiety Disorder-7 (GAD-7)

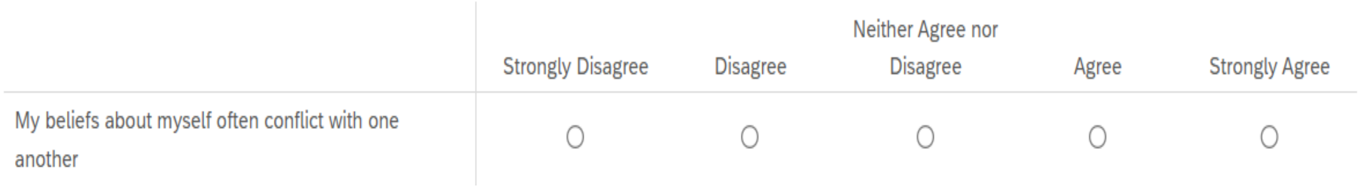
Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	○	○	○	○

The SCC was developed to establish if self-concept clarity is a continuous trait that could be measured (Campbell et al., 1996). The SCC demonstrated excellent internal consistency, test-retest reliability and face validity (Campbell et al., 1996). A further study by Glezakis et al. (2024) evidenced that the SCC was both a reliable and valid measure for assessing self-concept in people with a diagnosis of social anxiety disorder. This suggests that the SCC is a good measure for assessing the construct of self-concept in the participants in this study. The SCC consisted of twelve items which respondents were asked to rate on a five-point Likert scale (1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, 5=strongly agree; Figure 2.8). Items 1, 2, 3, 4, 5, 7. 8, 9, 10 and 12 are reverse scored. Participants could achieve a maximum score of 60. High total scores on this outcome measure indicated a greater sense of self-concept clarity.

Figure 2.8

Example of the Self-Concept Clarity (SCC)



	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
My beliefs about myself often conflict with one another	○	○	○	○	○

Procedure

Participants were provided with an information sheet (appendix E) which outlined the purpose of the study, what would be required and potential risks. Participants were then provided with a statement of consent and informed that completion of the study indicated consent (appendix F). Participants were made aware of their right to withdraw at any time.

Participants were asked to answer some demographic questions (age, gender, sexual orientation, ethnicity, living arrangements, level of education, employment status and religion) and to provide some background information on their physical and mental health. They were also asked to complete the questionnaires described above and a questionnaire related to attachment (attachment information was not analysed in this study). At the end of the questionnaire participants were asked to provide their contact details if they wished to be entered into a possible prize draw to win a £20 amazon voucher. Participants were also provided with the participant information sheet again and reminded of services they could contact if feeling distressed.

Data Collection

Data was collected using the questionnaires described above.

Data Analysis

Data collected from the questionnaires was cleaned. Any participants who did not complete over 85% of the online questionnaire were removed from the dataset. Any participants who had completed over 85% of the online questionnaire but had not completed the questions related to childhood trauma and the CDS were also removed. Any participant who incorrectly answered a minimum of three attention checks within the questionnaire were also deemed inaccurate and removed from the dataset.

Following cleaning of the data, tests of normality were conducted to determine if Pearson or Spearman's correlations were most appropriate. These tests indicated that all the data was non-parametric except for the SCC which was normally distributed. However, as all other data was not normally distributed. Spearman's Rho correlations in SPSS (version 28) were therefore used to calculate significant associations between the variables collected. To better understand some of the correlations observed and to see if DPDR symptoms can be predicted from various facets of the CTQ, religion and gender, multiple linear regressions were conducted.

To explore the findings further, a moderation and mediation analysis were both considered. A moderation analysis hypothesises that a predictor variable and its outcome is reliant upon a third variable which can alter the strength or direction of the relationship. A moderation analysis therefore helps to understand the strength or direction of the relationship between the predictor and outcome variable. On the other hand, a mediation analysis helps to understand how a mediating variable may influence the relationship between an independent and dependent variable. Mediation analyses are appropriate if assumptions are met, namely: direction (the mediating variable influences the outcome variable but the outcome variable does not affect the mediating variable), interaction (the effect of the mediating variable on the outcome variable does not change across different levels of the predictor variable), reliability (the mediating variable reliability is excellent) and confounding (no other predictor variable causes the mediating and outcome variable) (Judd & Kenny, 1981). Whilst not all assumptions were definitively met by the study, there was some evidence in previous studies where these assumptions had been met, for example, the temporal ordering of childhood trauma on DPDR or pathological dissociation, including depersonalisation and self-concept clarity and DPDR (Chiu et al., 2015; Lassri et al., 2022). An exploratory mediation analysis was therefore carried out to help understand how the mediating variable of self-concept clarity impacted on the relationship between aspects of childhood trauma and DPDR, depression and anxiety. The mediation analysis was followed by a Sobel test to establish whether self-concept clarity was a significant mediator in the relationship between aspects of adverse childhood experiences and DPDR experiences.

Ethical Considerations

University of Essex ethics was completed and approved via the Ethics Review and Management System (protocol number ETH2223-1827; appendix G). A participant information sheet outlining the aim of the study and requirement of participants was provided prior to completion of the questionnaire on Qualtrics. A statement of consent indicated that completion of the questionnaire was affirmation of consent to participate in the study. Debrief information was provided at the end of the questionnaire. It was highlighted that all participants had a right to withdraw prior to data analysis and if they chose to do so, all data pertaining to them would be removed. Participants were made aware that following data analysis, the data would have been anonymised and so the researchers would be unable to remove them. However, participants would be unidentifiable from the data.

Results

Sample Characteristics

Descriptive Statistics

A total of 124 participants responded to the questionnaire. To gather detail about the sample, participants answered some demographics questions at the start of the survey regarding age, gender, sexual orientation, ethnicity, religious backgrounds, and education. Participants were aged between 18 and 75 years old. 50% (n=62) of the sample identified with a White ethnic background whilst a further 37.1% (n=46) identified with an Asian background. 55.6%

(n=69) of the sample indicated that they were female. 78.2% (n=97) of the sample indicated that they identified as heterosexual. Approximately two thirds (67.8%, n=84) of the sample had attended university and gained a degree or higher qualification. 36.3% (n=45) of participants considered themselves religious with a further 21.8% (n=27) indicating that they considered themselves to be spiritual but not religious. A summary of the demographics are presented in Table 2.1 below.

Table 2.1

Sociodemographic Characteristics of Participants

Characteristic		*N*	%
Gender			
	Woman	69	55.6%
	Man	50	40.3%
	Other	5	4.0%
Ethnicity			
	White British or any other White background[a]	62	50.0%
	Asian or any other Asian background)[b]	46	37.1%
	Mixed/multiple ethnic background[c]	7	5.6%

Characteristic		*N*	%
	Black British or any other Black background[d]	4	3.2%
	Other ethnic group	4	3.2%
	No answer given	1	0.8%
Sexual orientation			
	Straight or Heterosexual	97	78.2%
	Bisexual	13	10.5%
	Gay or Lesbian	6	4.8%
	Other sexual orientation	4	3.2%
	Prefer not to say	4	3.2%
Living arrangements			
	Family[e]	56	45.2%
	Partner	32	25.8%
	Alone	18	14.5%
	Shared accommodation[f]	18	14.5%
Highest level of education			
	University – Bachelors Degree	44	35.5%
	Graduate or professional degree[g]	40	32.3%

Characteristic		*N*	*%*
	Some university but no degree	16	12.9%
	Secondary	11	8.9%
	Vocational or similar	10	8.1%
	Some Secondary	3	2.4%
Employment status			
	Working full-time	39	31.5%
	Student	25	20.2%
	Working part-time	21	16.9%
	Retired	13	10.5%
	Unemployed and looking for work	9	7.3%
	Other	9	7.3%
	A homemaker or stay-at-home parent	8	6.5%
Religious background			
	No religious background	39	31.5%
	Christianity	35	28.2%
	Hinduism	32	25.8%
	Islam	8	6.5%
	Other	6	4.8%
	Sikhism	2	1.6%
	Buddhism	1	0.8%

	Judaism	1	0.8%

Characteristic		*N*	*%*
Consider self to be religious			
	No	47	37.9%
	Yes	45	36.3%
	Do not identify with a religion but consider self to be spiritual	27	21.8%
	Other	5	4.0%
Diagnosis of other mental health conditions			
	Anxiety	64	51.6%
	Depression	52	41.9%
	DPDR	31	25.0%

Note. The mean age of participants was 19.85 years old (*SD* = 14.701).

All percentages have been rounded to 1.d.p.

[a]English/Welsh/Scottish/Northern Irish/British, Irish. Gypsy/Roma/Traveller, any other White background

[b]Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, any other Asian background)

[c]Mixed/multiple ethnic background (White and Black African, White and Black Caribbean, White and Asian, any other mixed/multiple ethnic background)

[d]Black/African/Caribbean/Black British (Any other Black/African/Caribbean background)

[e]Family (i.e. parents, grandparents, children, etc.)

[f]Shared accommodation (i.e. at university, shared flat, etc.)

[g]Graduate or professional degree (MA, MS, MBA, PhD, Law Degree, Medical Degree, etc.

Statistical analysis

Mean (M) and Standard Deviation (SD) scores

The Mean (*M*) and Standard Deviation (*SD*) scores were calculated for each of the completed questionnaires as detailed in the method section and indicated that the sample were experiencing mild levels of anxiety, moderate levels of depression and high levels of depersonalisation/derealisation, although this was just below clinical significance to indicate DPDR (Table 2.2). Felt Sense of Anomaly (FSA) scores were classified as being within an average range (Černis et al., 2024). Of the sample, 51.6% (n=64) reported that they had previously been diagnosed with anxiety, 41.9% (n=52) had a diagnosis of depression and 25% (n=31) indicated that they had received a diagnosis of DPDR (Table 2.1).

Table 2.2

Mean Scores, Standard Deviation Scores and Severity Levels for Cambridge Depersonalisation Scale (CDS), Patient Health Questionnaire-8 (PHQ-8) Generalised Anxiety Disorder-7 (GAD-7) & Felt Sense of Anomaly (FSA) Questionnaire

Questionnaire	*N*	M	*SD*	Severity
CDS[a]	124	66.01	60.79	-
PHQ-8[b]	124	11.41	9.51	Moderate
GAD-7[c]	124	9.38	8.49	Mild
FSA[d]	124	20.39	13.86	Average

Note. All mean and standard deviation scores have been rounded to 2.d.p.

[a] A total score of 70 or above indicates clinical significant depersonalisation and derealisation experiences most likely indicating DPDR (Sedeño et al., 2014).

[b] A total score between 10-14 indicates moderate depression, 15-19 indicates moderately severe depression and 20-24 indicates severe/major depression (Kroenke et al., 2001; Kroenke et al., 2009; Marvin, 2011).

[c] A total score between 5-9 indicates mild anxiety, 10-14 indicates moderate anxiety and 15-21 indicates severe anxiety (Spitzer et al., 2006).

[d] A total score between 0-28 indicates average FSA dissociation, 29-38 indicates elevated FSA dissociation, 39-48 indicates moderately severe FSA dissociation and 49-56 indicates severe FSA dissociation (Černis et al., 2024).

The Self-Concept Clarity (SCC;Campbell et al., 1996) questionnaire and the Childhood Trauma Questionnaire Short Form (CTQ-SF;Bernstein et al., 2003) were also administered. The SCC's mean score was 37.05 (*SD* = 11.39). Mean and Standard Deviation scores were also calculated for the familial and non-familial (NF) CTQ-SF individual subscales along with the range of scores (Table 2.3). The childhood trauma most experienced by the sample was emotional neglect, both familial and non-familial. This was followed by experiences of emotional abuse. When the mean scores of the overall sample were compared with the clinical cut off's for exposure severity, they indicated that the sample did not meet the clinical exposure severity cut off for any of the dimensions on the CTQ-SF (Bernstein & Fink, 1998).

Table 2.3

Mean and Standard Deviation Scores for Childhood Trauma Questionnaire-Short Form (CTQ-SF) Questionnaires

Questionnaire		*N*	M	*SD*	Range (Minimum-Maximum)	Exposure Severity
CTQ-SF						
	Emotional Abuse[a]	124	10.24	5.44	5-25	Minimal
	NF[f] Emotional Abuse	121	8.73	3.77	2-20	Minimal

Questionnaire		*N*	M	*SD*	Range (Minimum-Maximum)	Exposure Severity
	Emotional Neglect[b]	124	11.58	5.40	5-25	Minimal
	NF Emotional Neglect	123	11.64	4.21	4-20	Minimal
	Physical Neglect[c]	124	7.61	3.19	5-20	Minimal
	NF Physical Neglect	119	2.77	1.27	1-5	Minimal
	Physical Abuse[d]	124	6.94	3.30	5-24	Minimal
	NF Physical Abuse	120	4.72	1.50	3-12	Minimal
	Sexual Abuse[e]	124	6.69	4.02	5-24	Minimal
	NF Sexual Abuse	120	6.83	3.69	4-23	Minimal

Note. There are less participants who answered all the non-familial CTQ-SF questions, hence why participant numbers provided are different.

All mean and standard deviation scores have been rounded to 2.d.p.

[a] For the emotional abuse subscale, a score between 12 and 14 indicates low severity of exposure, a score of 15 indicates moderate severity of exposure and a score of 16 and above indicates severe exposure (Bernstein & Fink, 1998).

[b] For the emotional neglect subscale, a score between 14 and 16 indicates low severity of exposure, a score of 17 indicates moderate severity of exposure and a score of 18 and above indicates severe exposure (Bernstein & Fink, 1998).

[c] For the physical neglect subscale, a score between 9 and 11 indicates low severity of exposure, a score of 12 indicates moderate severity of exposure and a score of 13 and above indicates severe exposure (Bernstein & Fink, 1998).

[d] For the physical abuse subscale, a score between 9 and 11 indicates low severity of exposure, a score of 12 indicates moderate severity of exposure and a score of 13 and above indicates severe exposure (Bernstein & Fink, 1998).

[e] For the sexual abuse subscale, a score between 7 and 11 indicates low severity of exposure, a score of 12 indicates moderate severity of exposure and a score of 13 and above indicates severe exposure (Bernstein & Fink, 1998).

[f] NF refers to the non-familial abuse questionnaire subscales

Normality test

To determine the appropriate statistical test, a Kolmogorov-Smirnov test was conducted to assess the normality of the data. The results indicated that only the SCC showed a non-significant effect, D(118) = .076, *p*=.089 suggesting that the data for this questionnaire was normally distributed. However, all other outcome measures, including the familial and non-familial subscales of the CTQ were significant, $p<.05$ (Table 2.4) and so the researcher concluded that this data was not normally distributed. Consequently, Spearman's Rho correlations were selected due to the data being non-parametric.

Table 2.4

Kolmogorov-Smirnov (K-S) Test of Normality

Questionnaire		*Df*	D	*p*
CDS[a]		118	.164**	<.001
FSA[b]		118	.111**	.001
GAD-7[c]		118	.152**	<.001
PHQ-8[d]		118	.133**	<.001
SCC[e]		118	.076†	.089
CTQ-SF[f]				<.001
	Emotional Abuse	118	.168**	
	NF[g] Emotional Abuse	118	.118**	<.001
	Emotional Neglect	118	.141**	<.001
	NF Emotional Neglect	118	.085*	.036
	Physical Neglect	118	.211**	<.001
	NF Physical Neglect	118	.173**	<.001
	Physical Abuse	118	.266**	<.001
	NF Physical Abuse	118	.400**	<.001
	Sexual Abuse	118	.396**	<.001
	NF Sexual Abuse	118	.361**	<.001

Note.**Test is significant at *p*≤.01 level

*Test is significant at the *p*≤.05 level

†Test is non-significant at *p*>.05

[a]*Cambridge Depersonalisation Scale*

[b]*Felt Sense of Anomaly*

[c]*Generalised Anxiey Disorder-7*

[d]*Patient Health Questionnaire-8*

[e]*Self-Concept Clarity*

[f]*Childhood Trauma Questionnaire-Short Form*

[g]NF refers to the non-familial abuse questionnaire subscales

Relationships between Self-Concept Clarity (SCC), Cambridge Depersonalisation Scale (CDS), Felt Sense of Anomaly (FSA), Patient Health Questionnaire-8 (PHQ-8) and Generalised Anxiety Disorder-7 (GAD-7)

The relationship between scores on the SCC, CDS, FSA, PHQ-8 and GAD-7 were calculated using a Spearman's Rho correlation test. Significant negative correlations with large effect sizes were observed between the SCC and the CDS, *r*(119) = -.630, *p*<.001, FSA *r*(119) = -.693, *p*<.001, PHQ-8 *r*(119) = -.792, *p*<.001 and GAD-7 *r*(119) = -.685, *p*<.001. This indicated that a higher sense of self-concept clarity seems to relate to lower scores on outcome measures for DPDR, depression and anxiety. Significant positive correlations with large effect sizes were also observed between the other outcome measures (Table 2.5). This is in keeping with research which already indicates a positive relationship between the PHQ and GAD-7 (Spitzer et al., 2006; Teymoori et al., 2020), and a positive correlation between the CDS and FSA (Lofthouse et al., 2023). Some research has also shown positive correlations between clinical measures for depression and anxiety and depersonalisation (Michal et al., 2011) which was similarly observed here.

Table 2.5

Spearman's Rho Correlations for the Self-Concept Clarity (SCC) and Cambridge Depersonalisation Scale (CDS), Felt Sense of Anomaly (FSA), Patient Health Questionnaire-8 (PHQ-8) & Generalised Anxiety Disorder-7 (GAD-7) (n=121-124)

Outcome Measure		*SCC*	*CDS*	FSA	*PHQ-8*
CDS	Correlation Coefficient	-.630**	-	-	-
	P	<.001	-	-	-
FSA	Correlation Coefficient	-.693**	.868**	-	-
	P	<.001	<.001	-	-
PHQ-8	Correlation Coefficient	-.792**	.711**	.758**	-
	P	<.001	<.001	<.001	-
GAD-7	Correlation Coefficient	-.685**	.700**	.733**	.833**
	P	<.001	<.001	<.001	<.001

Note. All correlation coefficients have been rounded to 3.d.p.

**Correlation is significant at p<.001 level (2-tailed)

Relationships between mental health and childhood trauma scores

The effect of the subscales of abuse from the CTQ-SF on scores on the PHQ-8, GAD-7, CDS, FSA and SCC were also investigated using a test of Spearman's Rho correlations. Significant positive correlations with medium to large effects sizes were observed for familial emotional abuse and CDS scores, *r*(122) = .485, *p*<.001, PHQ-8 scores, *r*(121) = .549, *p*<.001, GAD-7 scores, *r*(121) = .433, *p*<.001, ČEFSA scores *r*(122) = .523, *p*<.001 and SCC scores *r*(121) = -.526, *p*<.001 . This suggests that those with a higher severity exposure to familial emotional abuse presented with higher levels of depersonalisation-derealisation, depression, anxiety and felt sense of anomaly, in addition to lower levels of self-concept clarity. Similarly, significant correlations for all four mental health questionnaires and the SCC were observed for familial emotional neglect, familial physical abuse, familial physical neglect, non-familial emotional abuse, non-familial emotional neglect, non-familial physical neglect and non-familial sexual abuse (Table 2.6). This suggested that people with experiences of childhood trauma of all types except familial sexual abuse were more likely to show symptoms of DPDR, depression, anxiety and felt sense of anomaly. Additionally, those with lower self-concept clarity are likely to endorse the above types of traumatic childhood experiences. The largest effect sizes (medium to large) were seen for familial and non-familial emotional abuse.

Table 2.6

Spearman's Rho Correlations between childhood trauma and depersonalisation, felt sense of anomaly, depression, anxiety and self-concept clarity (n=119-124)

		CDS^b	FSA^c	*PHQ-8*^{d}	GAD-7^e	SCC^f
Emotional Abuse	Correlation Coefficient	.485***	.523***	.549***	.433***	-.526***
	P	<.001	<.001	<.001	<.001	<.001
Physical Abuse	Correlation Coefficient	.223*	.310***	.295***	.238*	-.227*
	P	.013	<.001	<.001	.008	.012
Emotional Neglect	Correlation Coefficient	.446***	.452***	.420***	.300***	-.353***
	P	<.001	<.001	<.001	<.001	<.001
Physical Neglect	Correlation Coefficient	.366***	.359***	.343***	.292***	-.244*
	P	<.001	<.001	<.001	.001	.007
NF^a Emotional Abuse	Correlation Coefficient	.411***	.480***	.497***	.513***	-.442***
	P	<.001	<.001	<.001	<.001	<.001
NF Physical Abuse	Correlation Coefficient	.111 †	.193*	.109†	.081†	-.077†
	P	.227	.035	.237	.379	.404
NF Sexual Abuse	Correlation Coefficient	.242*	.184*	.193*	.196*	-.196*

	P	.008	.044	.034	.032	.033
		CDS[b]	FSA[c]	*PHQ-8*[d]	GAD-7[e]	SCC[f]
NF Emotional Neglect	Correlation Coefficient	.331***	.334***	.358***	.309***	-.193*
	P	<.001	<.001	<..001	<.001	.035
NF Physical Neglect	Correlation Coefficient	.413***	.357***	.321***	.302***	-.199*
	P	<.001	<.001	<.001	<.001	.030

Note. All correlation coefficients have been rounded to 3.d.p.

**Correlation is significant at $p \leq .001$ level (2-tailed)

**Correlation is significant at $p \leq .01$ level (2-tailed)

*Correlation is significant at the $p \leq .05$ level (2-tailed)

†Correlation is non-significant at $p > .05$

[a] NF refers to the non-familial abuse questionnaire subscales[b] Cambridge Depersonalisation Scale

[c] Felt Sense of Anomaly

[d] Patient Health Questionnaire-8

[e] Generalised Anxiety Disorder-7

[f] Self-Concept Clarity

Understanding the relationships between depersonalisation-derealisation and childhood trauma

As the correlations indicated that there is an association between early-life abuse and neglect (except non-familial physical abuse) and depersonalisation and derealisation experiences, multiple linear regressions were carried out to understand more about their associations. The study was particularly interested in the predictive power of the CTQ-SF subscales on depersonalisation and derealisation experiences when religion and gender were added to the model. The impact of familial emotional abuse on CDS scores was therefore explored using a two-step hierarchical regression analysis. The first step of the model solely looked at the effects of familial emotional abuse on CDS scores. This was statistically significant, $R^2 = .241$, Adj. $R^2 = .234$, $F(1, 112) = 35.61$, $p<.001$. Familial emotional abuse appeared to be a highly significant predictor for CDS scores, $\beta = .491$, $p<.001$. In the second step of the model, religion and gender were added to assess their effects on the relationship between familial emotional abuse and CDS scores. Religion focused on religiosity, determined by the question “do you consider yourself to be religious?”, rather than identifying faith i.e. Christianity. Religion had four levels, yes consider self to be religious, no do not consider self to be religious, do not identify with a religion but consider self to be spiritual and other. For the purposes of the regression, participants who had selected the other category were removed. Gender had three levels, man, woman and other. Participants who identified as other were removed from this regression as the focus was on those identifying as male or female. The model was less able to predict CDS scores, but continued to be significant, $R^2 = .261$, Adj. $R^2 = .241$, $F(3, 110) = 12.98$, $p<.001$. Familial emotional abuse continued to be a significant independent predictor, $\beta = .454$, $p<.001$. Neither religion nor gender independently significantly predicted CDS scores, $\beta \leq .134$, $p\geq.114$. This suggests that familial emotional abuse in the past is a significant predictor of experiences of depersonalisation-derealisation in the present, but this is not enhanced by including gender and religion/spirituality as predictors. All other types of abuse were also found to significantly predict CDS scores even when adjusting for religion and gender (Table 2.7; Table 2.8), except for non-familial physical abuse, which significantly predicted CDS scores only once religion and gender were added to the model. Non-familial physical abuse never independently predicted CDS score, however, β = .167, p=.080, while all the other types of abuse did independently predict CDS score, $\beta \geq .199$, $p \leq .030$.

While gender was never observed to be a significant independent predictor of CDS score in any of the subscale of abuse models, $\beta \leq .158$, $p \geq .099$, religion appeared to independently predict CDS scores in the models for non-familial emotional abuse, β = .180, p=.041, familial physical abuse, β = .215, p=.020, non-familial physical abuse, β = .209, p=.028, familial sexual abuse, β = .254, p=.006 and non-familial sexual abuse, β = .214, p=.020. Religion was not observed to be a significant independent predictor of CDS score in models of familial or non-familial emotional neglect and familial or non-familial physical neglect, $\beta \leq .180$, $p \geq .053$, similar to the model of familial emotional abuse mentioned previously.

Table 2.7

Multiple hierarchical regressions for significant abuse and neglect with Cambridge Depersonalisation Scale (CDS) Step 1 model

	R²	Adj. R²	*Df*	*F*	*p*
Emotional Abuse	.241	.234	1,112	35.61***	<.001
NF Emotional Abuse	.180	.172	1,109	23.86***	<.001
Physical Abuse	.045	.036	1,112	5.24*	.024
NF Physical Abuse	.028	.019	1,108	3.10†	.081
Sexual Abuse	.039	.031	1,112	4.56*	.035
NF Sexual Abuse	.098	.090	1,108	11.73***	<.001
Emotional Neglect	.216	.209	1,112	30.82***	<.001
NF Emotional Neglect	.109	.100	1,108	13.17***	<.001
Physical Neglect	.186	.178	1,112	25.52***	<.001
NF Physical Neglect	.158	.151	1,111	20.89***	<.001

Table 2.8

Multiple hierarchical regressions for significant abuse and neglect with Cambridge Depersonalisation Scale (CDS) Adjusted model with Gender and Religion

	R²	Adj. R²	*Df*	*F*	*p*
Emotional Abuse	.261	.241	3,110	12.98***	<.001
NF Emotional Abuse	.230	.209	3,107	10.66***	<.001
Physical Abuse	.109	.084	3,110	4.47**	.005
NF Physical Abuse	.107	.081	3,106	4.22**	.007
Sexual Abuse	.117	.093	3,110	4.86**	.003
NF Sexual Abuse	.161	.137	3,106	6.77***	<.001
Emotional Neglect	.242	.221	3,110	11.68***	<.001
NF Emotional Neglect	.160	.137	3,106	6.75***	<.001
Physical Neglect	.214	.192	3,110	9.96***	<.001
NF Physical Neglect	.189	.166	3,109	8.45***	<.001

Note. The value of F has been rounded to 2.d.p.

***Correlation is significant at $p \leq .001$ level

**Correlation is significant at $p \leq .01$ level

*Correlation is significant at the $p \leq .05$ level

†Correlation is non-significant at $p > .05$

[a] NF refers to the non-familial abuse questionnaire subscales

Note. The value of F has been rounded to 2.d.p.

***Correlation is significant at $p \leq .001$ level

**Correlation is significant at $p \leq .01$ level

*Correlation is significant at the $p \leq .05$ level

†Correlation is non-significant at $p > .05$

[a] NF refers to the non-familial abuse questionnaire subscales

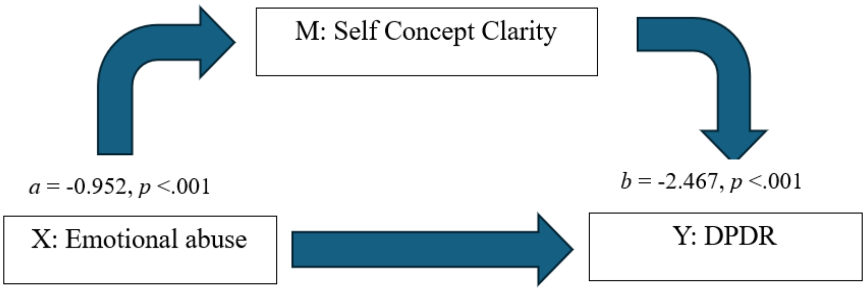
In summary, the association between types of abuse and CDS scores remained significant after adjusting for gender and religion. The weakest relationships were seen for physical abuse and familial sexual abuse, and the strongest relationships were seen for familial emotional abuse and neglect. Gender was not found to have an effect on CDS scores and consequently depersonalisation experiences. However, religion was shown to have a significant effect on CDS scores in some of the abuse models. This suggests that some level of religiosity or spirituality may influence experiences of depersonalisation for people who have experienced physical abuse, sexual abuse or non-familial emotional abuse.

Mediation analyses

Mediation analyses were conducted to explore whether the relationship between types of familial abuse (emotional abuse, emotional neglect & physical neglect) and mental health symptoms (DPDR, depression & anxiety as measured by CDS, PHQ-8 and GAD7) were mediated by self-concept clarity. The first mediation analysis (Figure 2.9) indicated that there was a significant negative effect of emotional abuse on self-concept clarity (a-path analysis), $b = -0.952$, $p<.001$. A significant negative effect of self-concept clarity on DPDR was also observed (b-path analysis), $b = -2.467$, $p<.001$. Additionally, a significant positive effect of emotional abuse on DPDR was observed (c'-path analysis), $b = 2.858$, $p<.05$. However, the mediation analysis also indicated that adding self-concept clarity into the model strengthened the relationship between emotional abuse and DPDR (c-path analysis), $b = -5.220$, $p<.001$. This appeared to be a partial mediation as both the c-path and c'path analysis were significant. This suggests that self-concept clarity partially mediates the effect from emotional abuse onto DPDR. A Sobel test was subsequently conducted to explore if the relationship between emotional abuse and DPDR remained statistically significant after including the mediator of self-concept clarity. This indicated that self-concept clarity remained a partial mediator in the relationship between emotional abuse and DPDR, $z = 3.954$, $ab = 2.349$, $p<.001$. This suggests that a lesser sense of self is a partial mediator in the relationship between emotional abuse and DPDR experiences. Similar significant effects were also observed for the mediating effect of self-concept clarity between emotional neglect (Figure 2.10) and physical neglect (Figure 2.11) and DPDR (Table 2.90).

Figure 2.9

Mediation role of self-concept clarity in the relationship between emotional abuse and DPDR



Direct effect, $c' = 2.858$, $p=.002$

Total effect, $c = 5.220$, $p < .001$

Indirect effect, $B = 2.349$, $p < .001$, 95% CI [1.184, 3.513]

Note. (N=124)

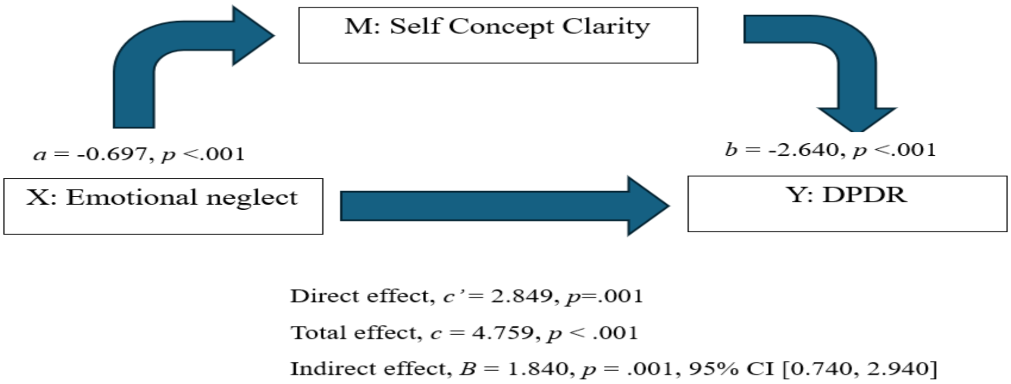
X indicates that this is the independent variable

Y indicates that this is the dependent variable

M indicates that this is the mediating variable

Figure 2.10

Mediation role of self-concept clarity in the relationship between emotional neglect and DPDR



Note. (N=124)

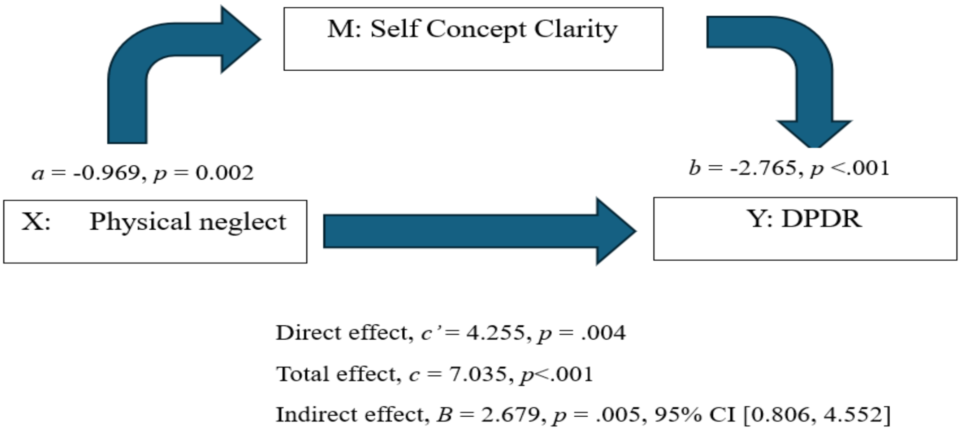
X indicates that this is the independent variable

Y indicates that this is the dependent variable

M indicates that this is the mediating variable

Figure 2.11

Mediation role of self-concept clarity in the relationship between physical neglect and DPDR



Note. (N=124)

X indicates that this is the independent variable

Y indicates that this is the dependent variable

M indicates that this is the mediating variable

Table 2.9

Mediation analyses for emotional abuse, emotional neglect, physical neglect and DPDR

	Emotional Abuse					Emotional Neglect					Physical Neglect				
Path Analyses	B	Effect	*p*	LCI	UCI	B	Effect	*p*	LCI	UCI	B	Effect	*p*	LCI	UCI
A-path	-0.952	-5.601	<.01	-1.288	-0.615	-0.697	-3.856	<.01	-1.056	-0.339	-0.969	-3.101	<.01	-1.588	-0.350
B-path	-2.467	-5.671	<.01	-3.328	-1.605	-2.640	-6.460	<.01	-3.449	-1.831	-2.765	-6.843	<.01	-3.565	-1.965
C'-path (direct effect)	2.858	3.153	<.01	1.063	4.653	2.849	3.333	<.01	1.156	4.542	4.255	2.972	<.01	1.420	7.091
C-path (total effect)	5.220	5.838	<.01	3.450	6.990	4.759	5.157	<.01	2.932	6.586	7.035	4.383	<.01	3.857	10.212
Indirect effect	2.349	3.954	<.01	1.184	3.513	1.840	3.278	<.01	0.740	2.940	2.679	2.803	<.01	0.806	4.552

Although self-concept clarity was observed to have a mediating effect between emotional abuse, emotional neglect and physical neglect and DPDR, similar effects were also observed for both depression (Table 2.10) and anxiety (Table 2.11). This suggests that self-concept clarity can mediate the effect of other mental health disorders and the effect is not specific to DPDR. However, there was one exception for the relationship between emotional neglect and anxiety. Here the requirements for a mediation analysis were not met as there was a non-significant direct effect of emotional neglect on anxiety, $b = 0.17$, $p>.05$. Consequently it is not possible to draw conclusions about a possible mediating effect of self-concept clarity in this relationship.

Table 2.10

Mediation analyses for emotional abuse, emotional neglect, physical neglect and Depression

	Emotional Abuse					Emotional Neglect					Physical Neglect				
Path Analyses	B	Effect	*p*	LCI	UCI	B	Effect	*p*	LCI	UCI	B	Effect	*p*	LCI	UCI
B-path	-0.561	-10.540	<.01	-0.666	-0.455	-0.591	-11.660	<.01	-0.692	-0.491	-0.602	-12.072	<.01	-0.701	-0.503

	Emotional Abuse					Emotional Neglect					Physical Neglect				
Path Analyses	B	Effect	*p*	LCI	UCI	B	Effect	*p*	LCI	UCI	B	Effect	*p*	LCI	UCI
C-path (total effect)	0.342	3.091	<.01	0.123	0.562	0.278	2.621	<.01	0.068	0.488	0.434	2.455	<.05	0.084	0.784
Indirect effect	0.534	4.933	<.01	0.322	0.746	0.412	3.642	<.01	0.190	0.634	0.583	2.998	<.01	0.202	0.965

Note. The A-path is the same as reported in Table 2.9.

A diagrammatical representation of the mediation analyses for emotional abuse, emotional neglect, physical neglect and depression can be found in appendix H.

Table 2.11

Mediation analyses for emotional abuse. physical neglect and Anxiety

	Emotional Abuse					Physical Neglect				
Path Analyses	B	Effect	*p*	LCI	UCI	B	Effect	*p*	LCI	UCI
B-path	-0.423	-7.271	<.01	-0.539	-0.308	-0.444	-8.302	<.01	-1.588	-0.350
C'-path (direct effect)	0.668	5.195	<.01	0.413	0.922	0.910	4.006	<.01	-0.550	-0.338
C-path (total effect)	0.261	2.154	<.05	0.021	0.501	0.470	2.481	<.05	0.460	1.360
Indirect effect	0.403	4.416	<.01	0.224	0.581	0.430	2.887	<.01	0.095	0.846

Note. The A-path is the same as reported in Table 2.9.

Emotional neglect is not reported as this did not meet the requirements for a mediation analysis.

A diagrammatical representation of the mediation analyses for emotional abuse, physical neglect and anxiety can be found in appendix I.

Discussion

This study was designed to build on previous research indicating a relationship between childhood trauma as measured by the Childhood Trauma Questionnaire (CTQ) and depersonalisation and derealisation. However, it is the first study to separately explore familial and non-familial childhood abuse and neglect on depersonalisation and derealisation experiences. Additionally, it is the first study to explore religion as a moderating factor and gender as a covariant in the relationship between childhood trauma and depersonalisation and derealisation. It also develops research which has previously investigated the role of self-concept clarity on psychological wellbeing and dissociation experiences. This study additionally explored the mediating role of self-concept clarity between certain subscales of abuse and depersonalisation and derealisation experiences which has not specifically been investigated before.

Significant results for the mediating role of self-concept clarity between emotional abuse, emotional neglect, physical neglect and DPDR were observed. The hypothesis that predicted that there would be a significant mediating role of self-concept clarity between abuse and DPDR experiences was partially accepted. The mediation analyses suggested that higher levels of self-concept clarity can reduce experiences of DPDR, if that person has experienced emotional abuse, emotional neglect or physical neglect. The mediating role of self-concept clarity on other types of abuse was not conducted due to their weaker correlations with DPDR. Hence, the hypothesis could not be accepted for all types of abuse. However, it is important to note that there also appeared to be a significant mediating role of self-concept clarity between these three types of abuse and depression. Additionally, the effects of emotional neglect and physical neglect on anxiety seemed to be significantly mediated by self-concept clarity. This suggests that higher levels of self-concept clarity play a role in reducing experiences of mental illness, not limited to DPDR, when there has been emotional abuse, emotional neglect or physical neglect. This supports the previous research by Evans et al., (2015) and Wong et al. (2019) who both evidenced that poorer self-concept clarity is related to mental health difficulties. Therefore, it is difficult to conclude that self-concept clarity plays a special role in mediating the relationship between emotional abuse, emotional neglect or physical neglect and DPDR experiences that is different from its observed mediating role in depression and anxiety. Nevertheless, it does highlight the possible protective nature of self-concept clarity in reducing mental distress, including for depersonalisation and derealisation experiences. This is similar to the findings of Lassri et al. (2022) who indicated the moderating role of self-concept clarity in the relationship between childhood sexual abuse and depersonalisation and derealisation experiences. It is therefore important to consider the possibly significant role of self-concept clarity in the relationship between childhood trauma and depersonalisation and derealisation experiences. However, it is also important to note that not all assumptions of the mediation analysis were met and therefore, the results may be a false representation of the role self-concept clarity plays in the relationship. For example, a temporal relationship between self-concept clarity and DPDR is unclear inferring that lower levels of self-concept clarity could be a reflection of the distress caused by depersonalisation/derealisation. Consequently, further exploration of the mediating role of self-concept clarity is required.

A two-step hierarchical regression analysis indicated that familial emotional abuse continued to be associated with higher Cambridge Depersonalisation Scale (CDS) scores when religion and gender were added in the second step of the model and was therefore predictive of depersonalisation and derealisation experiences. Nevertheless, religion and gender did not appear to significantly predict an effect on CDS scores, suggesting that religion and gender did not enhance the prediction of increased depersonalisation and derealisation experiences. Of the other types of abuse, only non-familial physical abuse was not significantly associated with CDS scores although this became significant when controlling for religion and gender. Overall, regressions indicated that gender did not significantly affect relationships between types of abuse and scores on the CDS. However, religion did appear to have a significant effect on relationships between some types of familial and non-familial abuse and CDS scores, indicating that religiosity or spirituality may increase the likelihood of experiences of depersonalisation and derealisation in these cases. Whilst some research has evidenced religiosity or spirituality as a protective factor in depersonalisation and derealisation experiences, for example Diego-Cordero et al. (2022), there is very little research into the effect of religion or spirituality on DPDR. Consequently, future studies may want to explore this finding in relation to sample participants with a clinical diagnosis of DPDR. Interestingly, no effect was observed of religion on the subscales showing the strongest correlations with depersonalisation and derealisation experiences, except for non-familial emotional abuse. Based on these observed findings, the hypothesis that there will be an effect of religion and gender on scores on the CDS was therefore rejected for gender, however, partially accepted for religion.

Significant negative correlations between Self-Concept Clarity (SCC) scores and scores on the Cambridge Depersonalisation Scale (CDS), Felt Sense of Anomaly (FSA), Patient Health Questionnaire-8 (PHQ-8) and Generalised Anxiety Disorder-7 (GAD-7) were observed, indicating that a higher sense of self-concept clarity is likely to reduce experiences of depersonalisation and derealisation, depression and anxiety. Based on these findings, the hypothesis that there would be a significant relationship between self-concept clarity and DPDR, depression, generalised anxiety and felt sense of anomaly was accepted. These findings are consistent with the work of Lassri et al. (2022), who demonstrated a negative relationship between self-concept clarity and depersonalisation and derealisation experiences in a group of people who had experienced childhood sexual abuse (CSA). However, this was not a finding observed in the group of people without experiences of CSA. This may be because Lassri et al., (2022) measured depersonalisation and derealisation experiences using the Dissociative Experiences Scale (DES; Carlson & Putnam, 1993). The Dissociative Experiences Scale (DES; Carlson & Putnam, 1993) has been shown to have reduced reliability, resulting from poor wording and issues with structure (Trujillo et al., 2024). Therefore, it may not have consistently picked up depersonalisation and derealisation experiences in the group without experiences of childhood sexual abuse. Additionally, their work did not investigate the relationship between other types of abuse and SCC scores and hence, may be another reason why this was only observed in the current research, which did explore all types of childhood abuse, both familial and non-familial.

Significant correlations between scores on the CTQ-SF and scores on the PHQ-8, GAD-7, CDS and FSA were observed for familial and non-familial emotional abuse, familial and non-familial emotional neglect, familial and non-familial physical neglect, familial and non-familial physical abuse and non-familial sexual abuse. However, no significant associations were observed between familial sexual abuse and depersonalisation and derealisation experiences, anxiety, depression and felt sense of anomaly. Based on these findings, the hypothesis that there would be a significant relationship between experiences of childhood trauma and experiences of DPDR, depression, generalised anxiety and a felt sense of anomaly was accepted for all types of abuse, except for sexual abuse where it was only partially accepted as this only seemed to demonstrate a relationship when it had taken place outside of the family. A similar systematic review exploring associations between childhood sexual abuse and depersonalisation/derealisation experiences found that over half the studies reviewed observed weak or non-existent relationships (Dunstan, 2025). Moreover, multiple studies in the systematic review showed stronger associations between childhood emotional abuse and emotional neglect (Dunstan, 2025). For example, King et al. (2020) showed that emotional abuse was the highest type of abuse correlated with depersonalisation/derealisation experiences. Therefore, the results in this study appear to support previous research findings indicating that emotional abuse and emotional neglect are predictors for depersonalisation and derealisation experiences, but sexual abuse is less likely to be related.

Strengths and Limitations

In Dunstan's (2025) systematic review, the studies reviewed had issues with ethnic and gender bias in their samples. The studies discussed had a primarily female sample and the majority identified as White/Caucasian (Dunstan, 2025). In contrast, although the present study still recruited a majority female sample, the split between male and female participants was closer to 50%. Furthermore, only half of the sample identified as being from a White/Caucasian background, with the next majority ethnicity being Asian. Additionally, previous study samples had mainly been university students or clinical samples, whereas this study recruited participants via a charity and therefore provided a wider sample from the general population. Moreover, participants were also recruited via SONA & Prolific which have a more global reach, hence may have helped to improve the sample's diversity. Consequently, this study seemed to have less issues with sample bias, making the findings more generalisable to the general population.

This study also utilised a purposive sampling technique. This was useful because it provided a greater sense of understanding about the depersonalisation and derealisation experiences of people who may have been living with DPDR. However, it may not have reached everyone with depersonalisation and derealisation experiences as it was advertised through one specific charity. Moreover, given that DPDR is often underdiagnosed or misdiagnosed (Michal, 2016), individuals with these experiences may not have been accessing the support of the charity and therefore this study could have missed these crucial experiences. Furthermore, the study specifically focuses on the link between DPDR and childhood trauma but does not explore why some people with experiences of childhood trauma may never develop experiences of depersonalisation and derealisation. Whilst the study also advertised for participants via the University of Essex, to mitigate some of this biased sampling, it may not have reached the appropriate sample. Therefore, future studies might wish to focus on specifically sampling people who have had experiences of childhood trauma or consider observing longitudinal data and the development of depersonalisation/derealisation following the reporting of adverse childhood experiences.

The sample size itself was good and a power analysis demonstrated strong power within the sample. This meant that the statistically significant results obtained were most likely to be accurately significant (Kemal, 2020). Moreover, multiple results were statistically significant at the $p<.001$ level, indicating that there was a 99% chance that the alternative hypothesis was appropriate (McLeod, 2023). Given the strong power of the study, it is possible to draw conclusions from these results and more confidently accept the hypotheses when statistically significant results were observed. This can help to add to the field of research on DPDR and support the understanding of this clinical phenomenon. However, it is important to note that multiple correlations and regressions were calculated without correction for multiple tests affecting the trustworthiness of results with larger p-values (e.g., p-values .001 and above for all 45 correlations between self-concept clarity, abuse and mental health variables).

Nevertheless, the researcher was confident that conclusions about most of the (stronger) reported relationships could still be accepted.

There were several limitations with the mediation analysis, for example sample sizes and issues with temporal ordering and the theoretical basis for the analysis method. A study by Sim et al. (2022) proposed that a sample size between 100 and 220 is required to detect a medium effect size for partial mediation using the delta method whilst a sample size between 100 and 200 is required to detect a medium effect size for full mediation using the delta method. In the case of the current study, the sample size of 124 participants in the mediation analysis should have been enough to detect a medium effect size, as a Sobel test which uses the delta method was carried out. However, the study did not have the required sample to accurately detect a small effect size. In addition to this, the current study did not show a temporal relationship between self-concept clarity and DPDR and made assumptions for the mediation analysis based on previous studies into self-concept clarity and DPDR. Further assumptions were also made about the mediating relationship based on high correlations. This is problematic because correlations only show a relationship but do not establish direction or a temporal order. High correlations may instead be an example of overlapping constructs although this is less likely in the case of this mediation analysis which had distinctive constructs for the predictor, mediator and outcome variables. Even so, high correlations in the mediation analysis may have created a false mediation when realistically self-concept clarity may not mediate the relationship between aspects of childhood trauma and DPDR. Therefore the results of the mediation analysis should be treated with caution and any observed effects should be explored in future research which can show a directional relationship between self-concept clarity and DPDR and in data which is normally distributed. This may be achieved by investigating a longitudinal dataset. Nevertheless, the mediation analysis does appear to show some interesting effects about how self-concept clarity may be present in the relationship between aspects of childhood trauma and DPDR which are worth exploring again in future studies.

This study utilised standardised measures with good reliability and validity. For example, the CTQ has shown "good test-retest reliability" (Bernstein, Fink, Handelsman, Foote & Lovejoy et al., 1994, p.1132) and has been found to be closely related to the childhood trauma interview. This suggests that the CTQ is an accurate retrospective measure of childhood trauma. Moreover, the validity and reliability of the CTQ has been observed in different populations, such as with Canadian undergraduate students (Paivio & Cramer, 2004) and Nigerian adolescents (Essien et al., 2018). Hence, the CTQ remains an accurate and reliable measure, even when used with a diverse population. Furthermore, numerous studies investigating the link between childhood trauma and depersonalisation/derealisation experiences have also made use of the CTQ (Dunstan, 2025). This study tried to add new dimensions of understanding by duplicating some of the CTQ items and asking participants to consider familial and non-familial contexts separately, an alteration that means we cannot claim complete methodological homogeneity with other studies. However, the novel insights gained from this may be seen as compensating for this limitation.

Another standardised measure used within this study was the CDS. The CDS was developed to replace other measures of depersonalisation, such as the Dissociative Experiences Scale (DES) which showed poor face validity and issues with addressing the complexity of depersonalisation (Sierra & Berrios, 2000). The CDS was found to accurately identify individuals with depersonalisation disorder and had excellent internal consistency. Moreover, since the development of the CDS, the questionnaire has been further adapted to assess for depersonalisation in other cultures, such as Spain (Molina-Castillo et al., 2006), Japan (Sugiura et al., 2009) and Greece (Kontoangelos et al., 2016). All these studies continued to show excellent reliability and validity, despite the cultural adaptations made to the questionnaires (Molina-Castillo et al., 2006; Sugiura et al., 2009 & Kontoangelos et al., 2016). Therefore, the CDS was an accurate measure of depersonalisation and derealisation experiences for a diverse population and as such ensured the reliability and validity of the findings.

Similarly, the self-concept clarity scale (SCC) is another validated and reliable measure of self-concept clarity. It accurately captures the extent to which individuals' beliefs about themselves are clearly defined, internally consistent (Campbell et al., 1996), and stable over time. Multiple studies across diverse populations have found that the SCC measures self-concept specifically and not sub-aspects, indicating that it measures a coherent and stable construct (Campbell et al., 1996; Wu et al., 2010; Mittal, 2015; Suszek et al., 2018). Furthermore, the SCC has shown good convergent and discriminant validity (Wu et al., 2010; Glezakis et al., 2024) showing positive associations with related constructs such as self-esteem and emotional stability. Consequently, the SCC is both a theoretically grounded and empirically robust measure of self-concept, that has been widely used successfully with multiple populations, meaning that this was an appropriate measure of self-concept in this study.

Although accurate measures of depersonalisation and derealisation and trauma were used, the study design required participants to think about their childhood experiences retrospectively. By asking participants to recall their past experiences and self-report these, the study may have been affected by recall bias. Recall bias suggests that participants may be more likely to retrospectively recall certain information such as exposure to traumatic experiences, based on their later life experiences (Prince, 2011). In the case of this study, participants may have appraised their childhood experiences to understand their present mental health difficulties, potentially leading to over reporting of childhood traumatic experiences on the

CTQ. This could have affected the internal validity of the study (Hassan, 2005), suggesting a strong relationship between DPDR and trauma when this relationship may be weaker. Alternatively, given the relationship between the freeze response during traumatic experiences and dissociation, it is possible that participants may have forgotten some childhood experiences of trauma and therefore these were not reported on the CTQ (Gillette, 2021), leading to a weaker relationship being observed. Consequently, it is difficult to draw accurate conclusions from the results. Nevertheless, the potential for recall bias can be minimised by using a validated measure of assessment (Hassan, 2005). As the CTQ is a validated and standardised measure, which has shown good internal consistency, it is an appropriate measure to retrospectively gather data on childhood trauma experiences and minimise recall bias (Hoeboer et al., 2025).

It is also important to note that a post-hoc test to correct for multiple comparisons was not completed. This may have led to a possible type 1 error when interpreting the results (Armstrong, 2014). Nevertheless, most of the initial results did indicate a high significance, Consequently, whilst the results should be treated with caution and it is important not to overemphasise the significant results, which may have been reduced with a post-hoc test, it is possible that these results would still have remained significant following any corrections.

This study did not look at the relationship between overall CTQ-SF scores and DPDR, anxiety, depression and felt sense of anomaly. This was because the researcher was interested in further understanding the specific relationships between different types of abuse on experiences of DPDR, anxiety, depression and felt sense of anomaly. The researcher was unsure whether correlations with a total score would increase understanding of the links between childhood trauma and DPDR. Even so, previous research into the CTQ-SF has demonstrated that each scale of the CTQ is significantly related to each of the other CTQ, excepting the sexual abuse and physical neglect scale which did not correlate with each other (Liebschutz et al., 2019). Hence, there may be an argument for future studies to look at the relationship between the total CTQ score and scores on the four questionnaires, to explore whether an overall relationship, with potentially more than one type of trauma may be an additional risk factor for increased experiences of depersonalisation/derealisation, anxiety, depression and felt sense of anomaly.

Implications

Research

Early studies such as Simeon et al. (2001) found that emotional abuse was a significant predictor for a diagnosis of depersonalisation disorder. In recent years, this finding has continued to be the case. For example, Laoide et al. (2018) found that a history of emotional abuse and emotional neglect was significantly related to experiences of depersonalisation. This was not observed with any other types of abuse during childhood. The current study appears to support these findings, indicating that emotional abuse and emotional neglect experienced in childhood, both familial and non-familial, is significantly related to clinical experiences of depersonalisation and derealisation. These correlations were significant at the $p<.001$ level and hence indicate a high level of confidence in these findings. Consequently, research should continue to focus on why emotional neglect and emotional abuse are most likely to cause experiences of depersonalisation and derealisation and what can be done to reduce the effect of this type of early childhood trauma on later psychological distress.

This study suggested that one explanation for why emotional neglect and abuse are likely to predict high levels of depersonalisation and derealisation experiences, is that this group of participants appeared to have lower levels of self-concept clarity. A study by Lassri et al. (2022) discovered that self-concept clarity protects people from depersonalisation and derealisation experiences when they had been exposed to childhood sexual abuse. However, they did not explore whether this was the case with other types of childhood abuse. Moreover, there is very little research investigating the effect of self-concept clarity on DPDR or childhood abuse on self-concept clarity. This study consequently attempted to address this gap in the research and suggested that self-concept clarity appears to play a significant mediating role. This may be because DPDR provides an experience of being separated from the self and therefore is likely to affect one's sense of self (Millman et al., 2024). Moreover, Wong et al., (2019) discovered that adverse childhood experiences can affect the development of a sense of self. This was later supported by Baroncelli et al., (2025) who similarly found that childhood trauma was likely to be related to an insecure attachment style which was subsequently linked with lower levels of self-concept clarity. Hence, these studies help to understand the current observed research findings, explaining that people who experience childhood trauma seem more likely to develop a lower sense of self-concept clarity and may therefore be less protected against DPDR which may then affect their sense of self further. Consequently, future research should focus on understanding more about the role of self-concept clarity in DPDR and consider how therapeutic interventions can increase self-concept clarity which may decrease derealisation and depersonalisation experiences.

Clinical

The findings regarding self-concept clarity indicate that a therapeutic intervention that focuses on an individual's sense of self could be helpful in reducing feelings of depersonalisation and derealisation, especially when their sense of self may be compromised through emotional abuse and neglect. Coutts et al., (2023) state that self-compassion is an indicator for a positive mental state. They found that self-concept clarity mediated the relationship between self-compassion and well-being. Hence, a therapy that addresses sense of self as part of self-compassion could be a useful intervention for DPDR. One such existing therapy is Compassion Focused Therapy (CFT). CFT believes that the “affect regulation system is poorly accessible in people with high shame and self-criticism [and] in whom the ‘threat’ affect regulation system is poor” (Gilbert, 2009, p.199), common in people with experiences of DPDR (Bezzubova, 2012) and childhood trauma (McLaughlin & Lambert, 2017). CFT aims to help people develop self-compassionate feelings and a self-compassionate voice (Leaviss & Uttley, 2014). In doing so, the hope is that this will help to soothe and regulate the threat system (Gilbert, 2009). In people with DPDR and experiences of childhood trauma, CFT could therefore be a helpful technique in regulating the threat system, reducing the opportunity for triggering feelings of depersonalisation and derealisation, whilst also building a sense of self through increased sense of self-compassion.

Conclusion

This quantitative study provides support for the theory that there is a relationship between childhood trauma and experiences of depersonalisation and derealisation, except in the case of familial sexual abuse. Two-step hierarchical regression analyses indicate that gender has no effect on these correlations but religiosity or spirituality does have an effect on the relationship between some types of abuse and DPDR. Emotional abuse, emotional neglect and physical neglect showed the strongest relationships with DPDR and all appeared to be mediated by self-concept clarity, suggesting that a stronger sense of self is linked with reduced experiences of depersonalisation and derealisation. However, self-concept clarity was also observed as a protective factor in experiences of depression and anxiety. The study itself appeared to have good power and strong levels of significance. It made use of validated outcome measures for childhood trauma, depression, anxiety, DPDR and felt sense of anomaly and therefore the results are both trustworthy and reliable. Consequently, this study can contribute to the understanding of DPDR and its relationship with childhood trauma and suggests avenues of further exploration, for example. the role of self-concept clarity on reducing depersonalisation and derealisation experiences.

Chapter 3

Chapter Overview

The following chapter outlines the qualitative study. The introduction section presents research and first-hand accounts of DPDR as a phenomenon. Research aims and questions are subsequently outlined and explained. The methodology section focuses on the design, setting, sample, materials, procedure, data analysis and ethical considerations. Trustworthiness for the qualitative study is appraised. A summary of sample characteristics and qualitative analysis is then presented in the results section. This is followed by a discussion section which explores the key findings of the study and makes recommendations for future research and clinical practice for DPDR.

Introduction

In the early 21st century, depersonalisation disorder was an "underreported and underresearched clinical phenomenon" (Baker et al., 2003, p428). Since this time, the diagnostic categories in the DSM and ICD have changed, and alongside this research has increased. However, Mirjat et al. (2024) affirm that DPDR remains underreported and underresearched, with not much understanding about causes, prevalence or treatment. Millman et al. (2024) assert that this is because there is still a scant number of studies that aim to explain the underlying causes of depersonalisation and derealisation experiences and how best to address DPDR. Part of the difficulty in conducting studies to explore this phenomenon is that the definition of DPDR is not clear. Depersonalisation and derealisation can be commonly experienced as a symptom of stress and fatigue in the general population or in people with different health conditions, both physical and psychological (Hunter et al., 2017). Similarly, depersonalisation and derealisation can be experienced as features of other primary disorders, such as panic disorder and major depressive disorder (APA, 2013). Symptoms of depersonalisation and derealisation also characterise the dissociative subtype of PTSD, which was added to the DSM-5 in 2013 (APA, 2013). The main distinction between the dissociative subtype of PTSD and DPDR is the presence or absence of symptoms of trauma. To receive a diagnosis of DPDR, another explanation for depersonalisation and derealisation experiences such as substance misuse, physical health conditions or another mental health disorder must not be present, according to the DSM-5 (APA, 2013). However, many of the potential causes of DPDR are associated with reasons to dismiss the diagnosis. For example, DPDR has been increasingly linked to trauma (Simeon et al., 2001; Armour et al., 2014; Laoide et al., 2018), depression (Hunter et al., 2004; Bertule et al., 2021) and anxiety (Lee et al., 2012). This was subsequently observed again in the study detailed in Chapter 2 of this thesis, which indicated that experiences of depersonalisation and derealisation were positively correlated with childhood traumatic experiences such as emotional abuse and symptoms of depression and anxiety. It is therefore possible that this is affecting the rate of DPDR diagnosis and the ability to identify and effectively research the disorder. Consequently, it is essential to explore first hand experiences of the journey to a DPDR diagnosis in people with comorbid mental health difficulties such as depression and anxiety.

First-hand experiences

To better understand DPDR, it is possible to explore qualitative accounts which describe first-hand experiences of the disorder. For example, Howorth (2020) describes his subjective experiences of DPDR which include somatic and physical symptoms of depersonalisation, such as losing feeling in his body. He talks about distorted senses, for example, feeling like he was staring through a tunnel and describes struggling to keep track of time passing, highlighting that these experiences became increasingly chronic, with each new episode enduring longer than the last to the extent that he continuously felt disconnected

(Howorth, 2020). Similarly, a 26-year-old named Lulu shared her experiences of DPDR including feeling like a robot, blurred vision and an out of body experience that left her feeling disconnected from reality (Uptas, 2019). Meanwhile, Natasha describes not recognising her face in the mirror, her vision also becoming distorted and a loss of control over functional movement (Rethink Mental Illness, 2022). This was a similar experience for Sarah and Iona who also did not recognise their reflections in the mirror and described a disconnection from their body (Eley, 2017; Gallagher, 2023). A common thread amongst all these experiences is the disconnection from the body, an unfamiliar feeling and the impact on the senses, all diagnostic features of DPDR according to the DSM-5 (APA, 2013).

Qualitative first-hand accounts of DPDR also shed some light on the experience of obtaining a diagnosis for DPDR. Swains (2015) describes how individuals experiencing DPDR visit health professionals on multiple occasions and are often met with bewilderment from professionals who have never heard of the disorder before. This leads to people who struggle with their symptoms in isolation for many years (Swains, 2015). This was the case for Sarah who explains that she saw up to 20 different healthcare professionals, all of whom were not aware of DPDR (Eley, 2017). Similarly, this pattern existed for Iona who was given other diagnoses such as dehydration and anxiety (Gallagher, 2023). She discovered DPDR online but was left without a formal diagnosis from health professionals (Gallagher, 2023). Natasha too visited many health professionals without receiving a diagnosis, leading her to complete her own online research to discover the condition (Rethink Mental Illness, 2022). Furthermore, Perkins (2021a) describes how he had to wait 10 years for a diagnosis and only discovered DPDR by coming across an online news article. Hunter and David (2022) explain that these experiences are common and that the term DPDR is often discovered online by people experiencing symptoms and then taken to GP's and healthcare professionals. Hence, people with DPDR experiences are not accessing a system where recognition and subsequent treatment of the disorder is easily facilitated.

Issues with diagnosis and treatment

The qualitative accounts above indicate that the healthcare system in the UK is ill-equipped to diagnose and address DPDR. Mind (2023) states that it can be difficult to receive a diagnosis for dissociative disorders such as DPDR because mental health professionals do not receive enough training in this area. Similarly, doctors are also limited by the training that they receive. For example, in 2017, a newly qualified GP stated that he had never received training on DPDR in medical school or in his specialised GP training (Eley, 2017). As a consequence of this lack of knowledge, the GP admits that he had wrongly diagnosed at least two patients (Eley, 2017). Furthermore, this limited knowledge of DPDR in the healthcare system means that DPDR is left to become increasingly distressing for service users, due to being untreated (Hunter et al., 2017). Moreover, this is resulting in an average wait of seven to 12 years for a primary diagnosis (Hunter et al., 2017).

In addition to issues with diagnosing DPDR, once this is diagnosed there are problems with where to access support and treatment (Eley, 2017). According to Eley (2017) there is one designated service in the UK to offer specialist treatment for DPDR and its resources are limited. Perkins (2021b) explains that at the time of writing, there were only two therapists working part time in the specialist service, reducing the ability to support a large number of people in a speedy manner. For Perkins (2021b), this meant that he waited approximately a year before beginning therapy. Moreover the service then had to apply for extra funding for more sessions adding a four-month delay to the therapeutic support (2021b). Eley (2017) affirmed that on average, the DPDR specialist clinic was seeing approximately 80 service users a year. Furthermore, in order to access this specialist service, the NHS must access funding from the local commissioning group, adding to the delay in referrals (Eley, 2017). Additionally, the DPDR clinic does not offer treatment to service users under the age of 18, despite the onset of symptoms most likely arising during adolescence (Eley, 2017). Consequently, there is no immediate specialist support available, allowing symptoms to fester and cause distress for many years.

Getting support for DPDR in other areas of the world is likely to be a different experience, although it can also present challenges. The health system in Canada follows a similar process to the UK and all citizens in Germany are required to have health insurance (Perkins, 2021b). Meanwhile in Australia the country funds half of all healthcare and has a designated mental health pathway to offer support for those struggling with their mental health (Perkins, 2021b). America on the other hand has an inadequate healthcare system, controlled by policy makers and insurance, according to Dr Guralnik (Perkins, 2021b). Consequently, it is likely to be challenging for a person in America struggling with DPDR to access specialist support in this area (Perkins, 2021b). Despite this, America is one of the leading countries researching DPDR and offering private expert services for support and treatment (Perkins, 2021b). Meanwhile, specialist services are more limited in other parts of the world where fewer experts mean that less is understood about the condition (Perkins, 2021b).

Treatment for DPDR

As well as issues with getting a diagnosis and then accessing support, there is also no clearly recognised treatment for DPDR (Medford et al., 2005). National Institute for Health and Care Excellence (NICE) guidelines for the specific treatment of DPDR do not exist (Perkins, 2021a). Depersonalisation and derealisation are recognised by NICE but only as a symptom of a functional neurological disorder or PTSD (NICE, 2024; NICE 2025). Hence, well-defined guidance for health professionals about how to treat DPDR is not available.

Despite this, Perkins (2021b) indicates that "the primary treatment for [DPDR] is psychological therapy" (p.155). Typically this is Cognitive Behavioural Therapy (CBT) which has the strongest evidence base (Meteyard, 2022). An early study by Hunter et al. (2005) found that CBT helped to reduce the severity of depersonalisation and derealisation and improved scores on outcome measures for dissociation, for participants with a DPDR diagnosis. Additionally, 29% of their participants were no longer classified as having DPDR by the end of the treatment (Hunter et al., 2005). Since this time, a specifically adapted model of CBT for DPDR has been created (Somer et al., 2013) and shown success in treating DPDR (Hunter et al., 2023; Farrelly et al., 2024). However, although CBT has shown positive results, research in this area remains sparse and systematic reviews have not provided further clarity about the most appropriate psychological treatment. Moreover, other psychological interventions such as schema therapy, compassion focused therapy (CFT), acceptance and commitment therapy (ACT) and eye movement desensitisation and reprogramming (EMDR) have also had a positive impact according to first-hand accounts (Perkins, 2021b). This demonstrates the wide range of treatments available to people experiencing DPDR, yet also highlights the lack of clarity on the best treatment to offer.

There are also proposed pharmacological treatments for DPDR. Despite Perkin's (2021b) assertion that psychological therapy is the principal treatment for DPDR, the recent systematic review by Wang et al. (2024) states that "considering the quality and quantity of evidence, medication is the main treatment for [DPDR]" (p.20). Some studies have suggested that lamotrigine may be an effective treatment. For example, lamotrigine is helpful in reducing DPDR when combined with the use of an antidepressant (Sierra et al., 2006) and lamotrigine did reduce depersonalisation experiences in the case of a 22-year-old woman with depersonalisation experiences (Rosagro-Escámez et al., 2011). A further systematic review discovered that lamotrigine was effective in treating DPDR in one study but not in another (Somer et al., 2013). Similarly fluoxetine showed no effect on DPDR although it did treat co-occurring anxiety (Somer et al., 2013). Although these early findings showed some success of medication as a treatment for DPDR it also highlighted that this was not consistent. Research in this area is still limited and as a result no specific medicine is evidenced to definitively treat DPDR (Meteyard, 2022). Furthermore, qualitative explorations of the treatment of DPDR by medication are limited and therefore this qualitative research can offer a deeper study of this treatment.

Another proposed treatment for DPDR is repetitive transcranial magnetic stimulation (rTMS). Much research has shown rTMS to be an effective intervention for treatment resistant depression (Karris et al., 2017). The first clinical trial of rTMS in the treatment of DPDR came from Mantovani et al. (2011). Twelve participants with a diagnosis of DPDR were recruited and given rTMS of which six (50%) of participants responded well to the treatment (Mantonvani et al., 2011). These six participants continued to receive rTMS for a further 3 weeks of which five of them showed a 68% reduction in experiences of DPDR (Mantovani et al., 2011). Since this early study, further research has explored rTMS as an intervention for DPDR. Jay et al. (2016) found that of seven participants who received rTMS, two fully responded to the treatment whilst four only responded partially. Additionally, a case study of a 30-year-old man with a diagnosis of depression and DPDR found that rTMS significantly lessened experiences of depersonalisation (Karris et al., 2017). A systematic review by Orrù et al. (2021) found that from eight studies meeting the inclusion criteria, rTMS seemed to be an encouraging intervention for reducing DPDR experiences. Despite these positive findings however, it is important to note that there were only a limited number of studies to review so it is difficult to draw any conclusions (Orrù et al., 2021). Additionally, study samples were relatively small and of these samples not all participants responded positively to rTMS (Orrù et al., 2021). Furthermore, even though rTMS is a NICE approved treatment for depression, only two mental health trusts in the UK had access to an rTMS machine as of 2016 (Smart TMS, 2016). Therefore, even if rTMS was a NICE recommended treatment for DPDR, it is likely that it would be difficult to access from state healthcare in the UK. Consequently, it is important to explore other low-cost and accessible potential interventions for DPDR.

Rationale for the qualitative study

Very little literature exists exploring the qualitative experiences of DPDR as part of a research study and so this qualitative study is an opportunity to explore themes amongst first-hand experiences, particularly in relation to the diagnostic journey and treatment. Existing research highlights issues with providing a diagnosis, such as a limited diagnostic criterion for DPDR and poor healthcare training which does not consider DPDR. Moreover, a dearth of specialist services and equipment exist to treat DPDR, leading to long waits and issues with funding and accessibility. Furthermore, an absence of clinical guidelines means that there is no clear approach to treating DPDR and research evidence for the best approach is limited by the quantity and quality of the studies (Wang et al., 2024). To support healthcare professionals and organisations such as the NHS with DPDR diagnosis and treatment, a study of first-hand accounts of DPDR can help with providing insight into the meaning of these experiences, understanding barriers to care and any therapeutic needs. By further understanding these experiences, clinical recognition of DPDR can be improved and guidance for future interventions can be developed, ensuring that patient care is at the heart of these systems and helping people with these experiences to access appropriate support from services. Moreover, gathering first-hand accounts from people outside of the UK can contribute to an understanding and improvement of diagnostic and treatment systems for DPDR internationally. Therefore, this study intended to answer the research questions outlined in Chapter 1, related to first-hand accounts of depersonalisation and derealisation and how these first-hand accounts inform an understanding of DPDR and potential treatment recommendations.

This study also intended to build on the initial quantitative study outlined in Chapter 2. A quantitative study can highlight statistical relationships i.e. correlations between aspects of childhood trauma and DPDR, however is not able to provide a subjective explanation of the underlying processes involved in the observed associations. Qualitative accounts of DPDR can explore how adverse experiences shape sense of self, influence dissociative coping strategies and impact on experiences of depersonalisation and derealisation. Understanding these processes can consequently help to inform clinical practice and theory, further contributing to better diagnostic systems and treatment approaches.

Methodology

Research Aims

This study aimed to explore first-hand accounts of depersonalisation and derealisation experiences by people with a diagnosis of DPDR. The researcher was interested in exploring how DPDR is experienced by people with a diagnosis, early childhood experiences and participants' sense of self, building on the study outlined in Chapter 2. Evidence has also shown that there are many challenges to overcome before receiving a diagnosis of DPDR and on average, individuals may be waiting between seven to 12 years for a primary diagnosis (Hunter et al., 2017). Consequently, the researcher hoped to explore participants' journeys to receiving a diagnosis and their opinions about what can be done to improve diagnosis and interventions for people with DPDR.

Ontology

For the qualitative component of the study, the researcher held a relativist ontological stance. Moon and Blackman (2017) explain that relativism is based on the belief that humans are responsible for creating reality in their minds. As a result, multiple realities exist dependent on an individual's experiences and perception of events, affected by factors such as place and time (Moon & Blackman, 2017). This stance was appropriate for the qualitative component of the study because the study aimed to investigate individual experiences of DPDR but acknowledged that each interviewee's reality and experience of DPDR was likely to be different. Consequently, holding this stance meant that the researcher could acknowledge the individual experience of DPDR for each interviewee and that they were unlikely to find one unique description or reality of DPDR. Instead, different words would be used to construct the individual realities of the interviewees and the researcher could use their analytical approach to look for moments or similar words where their realities may have been shared.

Epistemological Positioning

In alignment with the ontological stance, the qualitative study adopted an interpretivist position. An interpretivist epistemological position adopts qualitative methodology such as interviews to better understand the subjective experiences of participants related to the phenomenon being studied (Kriukow, 2024). This was relevant to the qualitative study as the researcher hoped to understand how DPDR was constructed and experienced by individuals with a diagnosis. In the qualitative study, DPDR was not treated as a measurable construct, but instead examined as a personal and subjective experience that is influenced by numerous factors. The interpretivist position helped the interviewer to engage in a conversation with the interviewee that attempted to create and construct knowledge about DPDR together (Pillay, 2024). Adopting this position also helped to give voice to the narrative experiences of people with a diagnosis of DPDR, which have rarely been heard in research into DPDR previously.

Axiological Positioning

I started by considering my own values and reasons for conducting the qualitative component of the research. I am currently a Trainee Clinical Psychologist working in the NHS. I have experience of working across a range of mental health services in a variety of roles including as a Support Worker, Assistant Psychologist and Trainee Clinical Psychologist. I consider supporting people to alleviate their emotional distress as a key part of my clinical role and one which I value considerably. In my role as an Assistant Psychologist I had the opportunity to work with a young person who was experiencing depersonalisation and derealisation. I witnessed how consuming these experiences were for the service user and how this had a debilitating effect on day-to-day functioning. Despite these clear experiences of depersonalisation and derealisation, the service user did not receive a diagnosis of DPDR and support for the symptoms of the disorder were limited. Consequently, it was difficult for the service user to experience any improvement in their emotional distress. Upon further exploration of the phenomenon, it was clear that research into DPDR was still minimal and that people were waiting years for a diagnosis, often turning to the internet to receive answers about their experiences instead (Perkins, 2021a; Perkins, 2021b). Furthermore, first-hand accounts indicated that DPDR was having a significant impact on the emotional wellbeing of people who were experiencing depersonalisation and derealisation symptoms. Therefore I hoped to make a meaningful contribution to the field of research into DPDR which could help improve the understanding and treatment of DPDR and subsequently support the alleviation of emotional distress.

In designing the study, I considered the areas posed by Alele & Malau-Aduli (2023) regarding axiological positioning. My role as a mental health professional meant that values already existed about treating all participants with respect. This led me to consider how I would value participants' contributions to the study and how they would be compensated for their time. Additionally, I was mindful of the power that I held in my position as an interviewer and the organisation that I was representing due to my current role in the NHS. I considered how to set up the interviews so that I did not cross over into the position of a therapist or NHS worker. At the start of the interviews, I introduced myself and my job title as a Trainee Clinical Psychologist but reminded participants that the interview was not a therapy session and that I was not expecting them to make any disclosures or share information that did not feel comfortable for them. This helped to underline my position as a researcher rather than a therapist. I also affirmed that my role was to gather information about interviewees' experiences of DPDR and highlighted that the interviewees were experts in their own experiences.

Design

This study is the qualitative component of the overall mixed methods study. It employed exploratory semi-structured interviews to gather comprehensive first-hand accounts of 10 participants' experiences of DPDR. Conducting interviews provided participants an opportunity to speak about their experiences of DPDR in their own words (Matthews & Ross, 2010). Semi-structured interviews in particular are useful because they are flexible and adaptive, meaning that the researcher can respond to data being gathered in the moment and adapt any interview questions based on this information, whilst still remaining focused on the overall aims of the study (Ruslin, 2022). Semi-structured interviews are typically the most common qualitative data collection tool in health-related research because they enable participants to express their thoughts, feelings and beliefs about personal experiences of a phenomenon (DeJonckheere & Vaughn, 2019), as was the case in this study. The qualitative study adopted an inductive approach which involved making initial observations in the data, looking for patterns or themes within the data and drawing general conclusions (Bhandari, 2022). This helped to provide a deeper understanding of participants' experiences of DPDR, complementing the data collection method.

Setting

Interviews were conducted via the online video conferencing platform Zoom, which the interviewer had free access to via their university. Virtual interviews were chosen due to their convenience and time efficiency (Theocharous, 2024). Conducting interviews online saved the interviewer and interviewee from spending significant amounts of money and time on travelling. This was particularly important because participants were from all over the UK and from other areas in the world, such as Spain and America and virtual interviews ensured these voices were captured. Furthermore, it was hoped that participating in interviews from the comfort of their home would help participants to feel less anxious (Theocharous, 2024) and more grounded, enabling them to participate in the interview in a present mindset. Participants were asked to be in a safe confidential space before the interview began and the interviewer checked that they were comfortable at the start of the interview. The interviewer also ensured that they were in a private space to protect the confidentiality of the interviewees and confirmed this with the interviewee at the start of the interview. Interviews were scheduled at mutually convenient times for both the interviewee and interviewer, taking into account time zone differences where necessary. Interviewees were reminded that they could take a break at any time during the interview. Some interviews were conducted in two parts due to the length of the first part of the interview. For the purpose of transcription and analysis, each interview was recorded with participants consent.

Sample

Participants who completed the questionnaire presented in Chapter 2 were asked to indicate whether they would be happy to complete a follow up study about their journey to a clinical diagnosis of DPDR. These participants were all aged 18 or over as this was a requirement for completion of the questionnaire. Participants were required to self-report that they had received a diagnosis of DPDR. Participants had also been asked to complete the Cambridge Depersonalisation Scale (CDS; Sierra & Berrios, 2000) during the questionnaire. A score of 70 or above on the CDS indicating clinical DPDR (Sierra & Berrios, 2000), in addition to the indication that the participant had received a diagnosis of DPDR was used to assess whether the participants were eligible for the follow up interview. Sixteen participants indicated that they were happy to be considered for the follow up study and met the criteria for DPDR on the CDS. All 16 potential participants were contacted via email of which 12 responded. Two of the 12 participants indicated that they were no longer able to take part, leaving a final sample size of 10. Hennink and Kaiser (2022) evidenced that data saturation can be reached with an average of 9 to 17 interviews, hence the researcher determined that the sample size was sufficient.

Materials

Access to Zoom and its recording and transcription function was required for completion of the interviews. An interview guide (appendix J) was also established based on previous research into DPDR and the findings from the quantitative component of the overall study. For example, questions on religion and sense of self were added to gain a greater understanding of the role of religion and self-concept clarity in DPDR experiences.

For the analysis of the data, the researcher utilised NVIVO (version 14). NVIVO was chosen to aid the qualitative analysis process, ensuring efficient and effective coding (Zamawe, 2015).

Procedure

The researcher aimed to ensure a variety of experiences by considering demographic data and details about age of onset of disorder and other mental health and physical health difficulties. The potential interviewees were contacted via email (appendix K) to ensure that they still wished to take part. They were then provided with an information sheet detailing the purpose of the interview, how their data would be used and any risks involved (appendix L). At the same time, participants were emailed a consent form which they were asked to sign and return to the interviewer prior to the interview (appendix M). Before conducting the interview began, participants were asked verbally whether they still consented to the study. Following the interview, participants were provided with a debrief sheet reminding them of key information from the participant information sheet (appendix N). Participants were also reimbursed for their time with a £10 amazon voucher.

Data Collection

Ten participants were interviewed using a semi-structured interview. The aim of this interview was to provide more detail about their individual story of DPDR, their childhood experiences and their journey from experiencing symptoms to receiving a diagnosis. Whiting (2008) outlines different phases of interviews which are "building rapport … apprehension phase … exploration phase … co-operative phase … participation phase … [and] concluding the interview" (p.37-38). Whiting (2008) suggests that building rapport with participants is present at every phase of the interview. In the apprehension phases, participants may be uncomfortable about the process and content of the interview (Whiting, 2008). Consequently the researcher clearly outlined the process of the interview and how it would be carried out to help put interviewees at ease. Additionally, DiCicco-Bloom and Crabtree (2006) propose that the initial interview question should allow the participant to explore the question comprehensively and broadly whilst also remaining focused on the research aims and questions. Hence, the interviews began with the question "could you tell me about your experience of depersonalisation derealisation disorder?" This could then be followed up with prompt questions, such as "when did you first notice experiences where you felt the world was not real or you were not real?" In the exploration phase, the questions should remain open-ended but provide the interviewee with opportunities to describe their experiences in greater detail (DiCicco-Bloom & Crabtree, 2006; Whiting, 2008). In this stage of the interview, participants were asked to describe their experiences of DPDR, how they cope with these experiences and how past childhood experiences and development of their sense of self might have impacted on DPDR experiences. The co-operative phase is an opportunity for a free dialogue to emerge between interviewer and interviewee (Whiting, 2008). In this phase the interviewer was able to follow the interviewee's lead, asking relevant follow-up questions based on the interviewee's responses. The majority of the interviews lasted over an hour and so the participation phase was often reached, where interviewees were able to guide the interviewer through their experiences (DiCicco-Bloom & Crabtree, 2006; Whiting, 2008) and talk about how DPDR could be better diagnosed and treated in the future. In the concluding the interview stage, Whiting (2008) suggests that the interview should come to a natural end for both interviewer and interviewee. The interviewer always made sure to thank the interviewee for their time and candidness about their experiences, which was an important part of the concluding the interview stage (Anderson, 1991). An example interview which demonstrates the applicability of the interview guide and process is provided in (appendix O).

All interview recordings were stored securely on a password protected hard drive for the duration of the study and will be automatically deleted one year after the interview took place. Participants were also made aware that the interview transcripts may be deposited in a research data repository.

Data Analysis

Reflexive thematic analysis as proposed by Braun and Clarke (2019) was conducted to analyse the interview data. Reflexive thematic analysis was chosen as it is an approach that effectively discovers relationships and meaning within large datasets (Dechalert, 2024). In their original paper, Braun and Clarke (2006) outline a six stage process for thematic analysis. In the initial stage, the researcher familiarised themself with the data. Although transcripts had been produced by Zoom, the researcher went through each transcript to check their accuracy in detail. Doing this helped the researcher to notice emerging patterns across the dataset. In stage two, initial codes were generated. Codes were both semantic and latent to usefully understand the content of the qualitative data (Byrne, 2022). Once all codes had been generated, they were exported from Nvivo into an excel document. This helped the researcher to see which datasets the code was present in and the quantity of references to a particular code across all interview transcripts. Clusters of related codes were then matched to different research aims (appendix P). When the codes were clustered, the researcher began stage three of searching for the themes. The researcher appraised all the clusters and summarised the idea that each cluster represented (appendix Q). The researcher then started to notice patterns across the ideas generated and began to establish initial themes. In stage four, the themes were reviewed to ensure that they met the overall research aims and questions (appendix R). These themes were subsequently defined and labelled. The researcher then produced the final analysis choosing appropriate quotes from each transcript to illustrate each theme. Braun and Clarke (2019) advise that reflexive thematic analysis involves constant "questioning and querying [of] the assumptions … [made] in interpreting and coding the data" (p.594). This was true in the case of this study, as the data was reviewed multiple times and initial themes were dismissed whilst others were adapted and new ideas were generated. Ayre and McCaffery (2022) explain that this querying and reflection in addition to acknowledgment of the researcher's positioning, helps create trustworthiness in the findings of the thematic analysis.

Ethical Considerations

University of Essex ethics was completed and approved via the Ethics Review and Management System separately for the interview stage (protocol number ETH2223-1623; appendix G). A participant information sheet outlining the aim of the interviews and details about how they would be conducted was provided prior to interview. Participants provided verbal consent to participate which was recorded via zoom. At the end of the interview, debrief information was once again provided with a reminder of support services they could access if needed. Participants' right to withdraw at any time was highlighted. Pseudonyms were also provided for each participant to protect their anonymity.

The researcher planned to pause or terminate the interview if any interviewee exhibited high levels of distress during the interview. The researcher also planned to support the participant to re-ground themselves using grounding techniques such as mindful breathing if needed.

Results

Interviews

A total of 16 participants provided their details at the end of the survey, all of whom were contacted to complete a follow up interview. Of the 16 contacted via email, 12 people responded, two of whom indicated that they were no longer able to take part. This meant that a total of 10 participants were interviewed about their experiences of DPDR. This consisted of seven (70%) females, two (20%) males and one (10%) person who identified as non-binary. Most participants lived in the United Kingdom and had experience of the NHS healthcare system. However, three of the participants lived abroad, of which two had no experience of the NHS. Despite this, their testimony was important in describing the experience of DPDR and what it was like to access help in other countries. All of the 10 (100%) participants reported a diagnosis of either depression or anxiety. Of these participants, seven (70%) reported diagnoses of both these disorders, in addition to DPDR. A summary of the sample characteristics is provided in table 3.1.

Table 3.1

Sociodemographic Characteristics of Participants

Characteristic		*N*	*%*
Gender			
	Female	7	70%
	Male	2	20%
	Non-Binary	1	10%
Ethnicity			
	White British or any other White background[a]	7	70%
	Mixed/multiple ethnic background[b]	3	30%
Religious background			

	Christianity	5	50%
	No religious background	4	40%
	Other religious background	1	10%
Characteristic		*N*	*%*
Diagnosis of Autism or ADHD			
	Autism	2	20%
	ADHD	4	40%
	Neither	4[c]	40%
Diagnosis of other mental health conditions[d]			
	Anxiety	9	90%
	Depression	8	80%
	Obsessive Compulsive Disorder	2	20%
	Post-traumatic stress disorder	2	20%
	Borderline personality disorder	1	10%
	Eating disorder	1	10%

Note. The mean age of participants was 31.1 years old.

[a] English/Welsh/Scottish/Northern Irish/British, Irish. Gypsy/Roma/Traveller, any other White background

[b] Mixed/multiple ethnic background (White and Black African, White and Black Caribbean, White and Asian, any other mixed/multiple ethnic background)

[c] Two of the participants who did not have a diagnosis of either ADHD or autism did discuss displaying traits of these conditions

[d] Some participants reported more than one mental health condition

Thematic Analysis

Reflexive thematic analysis was conducted adopting Braun and Clarke's (2019) approach as described in the methodology section above. Six themes and nine sub-themes answering the research aims and questions were generated following an intensive coding and analysis process (Table 3.2). All themes and sub-themes identified during the analysis are outlined below table 3.2 with supporting quotes from the ten interviews. Each participant selected a pseudonym which they are referred by throughout the interview and analysis.

Table 3.2

Table of themes and sub-themes

Number of theme	Name of theme	Sub-themes
1	Detachment from reality	All encompassing nature of depersonalisation and derealisation experiences

		Perception of self and identity

Number of theme	Name of theme	Sub-themes
2	Interconnected nature of anxiety, depression and DPDR	-
3	Development and maintenance of DPDR	-
4	Experience of seeking help	Lack of knowledge about DPDR NHS VS Private healthcare
5	The impact of limited knowledge and understanding of DPDR	Hopelessness Left to seek own answers The value of a diagnosis
6	Expectations of the healthcare system	Help available when asking More education and research

Theme 1: Detachment from reality

Participants talked about what it feels like to experience depersonalisation and derealisation both in the present day and at the onset of the disorder. They described a constant sense of being disconnected from the world, themselves and others.

> "…started to feel detached, unreal, like I was, I was convinced I was in a dream" (Louise)

> "I was just feeling so dizzy and detached and spaced out" (Hamilton)

> "It is a constant light-headedness and a detachment from everyone around me." (Imogen)

For some depersonalisation and derealisation manifested as feeling like a robot, a ghost or an alien, whilst for others, it was an out of body experience.

> "…it felt like I was like a robot" (Lourdes)

It seemed that the experience had not changed greatly between the onset of experiences and the way they experienced depersonalisation and derealisation in the present day and participants typically described the experience as chronic.

> "...it's never stopped … it's not sort of like, yeah, episodic, it's just continued at a pretty similar err level." (Lucy)

> "...it's just stayed with me and it's been pretty chronic. Not really like episodes, just like a haze … the severity of it ranges depending on the day and certain things in my life that might make it worse. But for the first year it was pretty severe and debilitating…" (Annie)

> "...it is chronic … it's like eight years with this strange sensation all the time" (Lourdes)

> "Once it hits, it's like a dam's broken … it's very much constant or it feels constant" (Liam)

All-encompassing nature of depersonalisation and derealisation experiences. As interviewees described this detachment from reality, it became clear that it affected all their senses including sight and hearing and even their perception of time. In turn, this seemed to reinforce the sense of detachment. All-encompassing nature of depersonalisation and derealisation experiences therefore emerged as a sub-theme, capturing the experience of their senses being taken over, in addition to the chronic nature of the disorder. Vision was a particular concern for some of the participants, who had even been to the optician to have their eyesight checked.

> "…the environment just looked completely different and just distorted." (Annie)
>
> "I kept going to get my eyes tested" (Louise)
>
> "…your limbs don't feel like they belong to you. Your … perception of time is messed up." (Lucy)
>
> "My hearing was kind of muffled…" (Louise)
>
> "…for me it felt constant in everything. From the moment I woke up to the moment I went to sleep." (Liam)

Perception of self and identity. A second sub-theme about participants' sense of self and identity emerged from the interviews. Participants discussed how early exposure to adverse childhood events such as abuse affected the development of their sense of self and identity.

> "I was made to not feel good enough and I was made to feel like an object and I was used like an object … I didn't put any value in me or how do I feel, or what do I want?" (Taylor)

> "Your dad is your aggressor … you feel like a toy of your dad. You're not an individual … you don't feel identity" (Lourdes)
>
> "I do remember questioning if I was enough a lot." (Louise)

This sense of self was further impacted by the disconnection and detachment aspects of DPDR. For example, Rebecca described how she didn't know what it felt like to be her without dissociation. Meanwhile, for Taylor DPDR allowed her to disconnect from her sense of self in a protective manner, allowing her to "continue not to know who [she is]". Furthermore, Lucy described her sense of self in the third person, assigning qualities to an external Lucy that was a shadow of herself, as a result of the disconnection caused by DPDR experiences. For most participants, their experience of disconnection from the world, caused by DPDR, supported them to find a new sense of self. For some this was through a relationship with religion and God, whilst for others was discovered via therapy and learning to understand the DPDR. This appeared to help manage some of the constant DPDR experiences and reduce the disconnection.

> "My relationship with God has kept me grounded and kept me alive … I've now sort of veered towards an identity of who I am in him" (Imogen)
>
> "I feel like I have more identity. I know myself. So that's why I'm not having this depersonalisation sensations…" (Lourdes)
>
> "…the DPDR situation. It just forced me to have a different perspective and outlook on life and force me to like get to know myself very well. I feel like I found like a new sense of self …" (Annie)

> "I'm starting to notice all these little things, but I'm not quite sure what parts of it are me or not me. So I'm still kind of in the learning stage of … what am I now noticing that actually is [DPDR]?" (Rebecca)

> "I have a good idea of who I am now … the derealisation, all that stuff has help… required me to try to work out what the hell is going on…" (Liam)

For those who did not think they had discovered a new sense of self, this was because they already described having a clear identity prior to the onset of DPDR.

> "I already got … had my sense of self before [DPDR], so it didn't change anything really." (Hamilton)

Theme 2: Interconnected nature of anxiety, depression and DPDR

Another theme that became apparent was the interconnected nature of anxiety, depression and DPDR. All interviewees had experienced some form of anxiety and depression, with most having received a formal diagnosis of at least one of these conditions at an earlier point in life, or whilst they were seeking support for DPDR. Anxiety and depression were also both present in the symptoms of DPDR, as described by the interviewees.

> "a lot of my DPDR symptoms, if you go through the yes/no route, you're gonna get out with depression and anxiety." (Shawn)

> "…there was like moderate depression which I genuinely didn't think I had, but it was just because of the way the anxiety was making me feel and the depersonalisation…" (Hamilton)

> "…whenever I get anxious … it's worse. It just flares up a lot more and I feel like they're very connected in that way." (Annie)

In particular, anxiety and panic appeared to be a trigger for DPDR but was also responsible for perpetuating depersonalisation and derealisation experiences. Some of the participants had experienced panic attacks at the onset of their depersonalisation and derealisation experiences.

> “it’s definitely a sort of a response to high stress levels.” (Hamilton)

> “…the derealisation naturally makes you freaked out … but also it seems to run on that. It gets worse and worse the more you … let the anxiety spiral…” (Liam)

On account of this interconnectedness, it seemed to make it more difficult for DPDR to be recognised when participants sought help for their experiences. Participants described how their DPDR would often be misdiagnosed as other mental health difficulties such as depression, anxiety or PTSD. Consequently, therapeutic interventions would also focus on reducing the anxiety and depression, which was helpful to some extent, but did not address the depersonalisation and derealisation experiences which were continuing to cause distress. This was particularly true for a Cognitive Behavioural Therapy (CBT) intervention, which many participants had engaged in, but had not improved DPDR.

> “…nobody else even suggested that this is what this could be. It was all very much kind of anxiety, it’s depression.” (Rebecca)

> “a general misunderstanding and a misdiagnosis of the condition in that it was seen as severe anxiety…” (Imogen)

> “…although [CBT] has taught me a lot about anxiety, I do still have depersonalisation derealisation and that hasn’t even depleted at all.” (Louise)

Theme 3: Development and maintenance of DPDR

In addition to anxiety, participants identified other factors which seemed to be playing a part in the development and maintenance of DPDR. One common aspect was trauma experienced during childhood which some recognised as the basis of their DPDR.

> "…my stepdad did a few things to me like push me up against walls and stuff like that … it was abusive" (Taylor)
>
> "…you've done something wrong … [Mum's] going mad about it, to the point … it's physically grabbing you, throwing you on the floor …" (Rebecca)

Whilst many participants had experienced abuse and a lack of safety in their homes growing up, for others trauma was related to events outside of their home. For example, Lucy described having many operations for a cleft lip and palate during childhood. She expressed feeling overwhelmed with panic prior to these operations causing high levels of distress which led to her being repeatedly restrained. For Shawn, they had similarly grown up in a stable home but had belonged to a religious group and described the messages they received about themselves from this group as being traumatic.

Another trigger and maintenance factor for DPDR identified by many of the participants was drug use, in particular cannabis. Liam and Imogen articulated that cannabis is a significant trigger that people identify for DPDR. Drug use also appeared to increase anxiety and panic, likely being responsible for triggering and maintaining the DPDR.

> "…it started for me after I had like a panic attack after or during smoking marijuana" (Annie)
>
> "I just smoked loads of [cannabis] in one go … had a really really big panic attack from that … that sort of triggered it all" (Hamilton)

For Annie, cannabis use was also a temporary solution for DPDR, helping to provide a connection to her feelings. She also described how her experience of DPDR was like being on drugs and so smoking cannabis provided a real explanation for the way she was feeling, helping to normalise the depersonalisation and derealisation experiences.

> "So by smoking [cannabis], it was kind of helping me, at least have like a connection to what I was feeling and it made me feel a little bit nor… more normal …" (Annie)

Transitions was an additional factor that participants noticed increased anxiety and depersonalisation and derealisation experiences. This was related to events such as starting secondary school or moving away for university, environments and people. For example, one of Louise's first experiences of depersonalisation and derealisation took place when she went on holiday and was in an unfamiliar room.

> "…it was a bit unfamiliar to me … I was aware when I went to sleep that I wasn't in my room … that was probably like almost an anxiety thing." (Louise)'

> "…whenever anything different that is out of my schedule shifts … it kind of just sparks [DPDR] up a little bit." (Annie)

An element indicating susceptibility to developing DPDR was neurodivergence. Some participants had received a diagnosis of ADHD or autism, generally during adulthood, at a similar time to DPDR diagnoses. For those who did not have a diagnosis of ADHD or autism, traits of neurodivergence had been identified and other family members had received diagnoses. Participants noticed that traits of ADHD and autism were present in their depersonalisation and derealisation experiences, even if they were not formally diagnosed as neurodivergent, contributing to the maintenance of DPDR.

> "…when I feel out of sync with the world … some of that's being neurodivergent" (Shawn)
>
> "…it's the brain fog and the concentration [which overlap with the depersonalisation and derealisation]" (Rebecca)
>
> "…they all fed into each other. I think that constant frantic searching for … to change things or checking in on stuff as well, is the speed that my brain seems to function…" (Hamilton)

Theme 4: Experience of seeking help

All participants described the process of seeking help through their local healthcare system. Most approached their doctor as the first step in this process.

> "…the GP is sort of your interface with the system" (Shawn)
>
> "I went through my GP" (Taylor)

Lack of knowledge about DPDR. Participants expressed that when they approached healthcare professionals for support with their depersonalisation and derealisation experiences, they were often met with dismissiveness, mislabelling and a lack of knowledge amongst healthcare professionals about DPDR, hence the emergence of this sub-theme. Often this poor understanding of DPDR prevented an earlier diagnosis.

> "…my psychiatrist at the time … was more than happy to put it down to trauma, or … the anxiety levels" (Lucy)
>
> "my first therapist told me that like this is post-traumatic stress" (Lourdes)
>
> "…the main kind of obstacle I came up against was people hadn't heard of it" (Louise)

> "I think the main thing [preventing a diagnosis] is just the lack of knowledge and training and education on [DPDR]" (Annie)
>
> "…it's the understanding of it from GP … GP level, which just doesn't seem to be there …" (Hamilton)
>
> "…it was kind of hand waved away…" (Lucy)

A lack of knowledge amongst healthcare professionals of DPDR also meant that there was an uncertainty about how to treat DPDR, both with therapy and medication. Many participants had been offered CBT therapy which did not focus on their DPDR experiences.

> "[CBT] was very focused on solutions … it felt very surface level" (Taylor)
>
> "…they're just trying all these different medications, and it's like … nothing fit…" (Rebecca)

Alternatively, given that DPDR was not always diagnosed and was instead attributed to trauma, depression and anxiety, interventions would often focus on treating these disorders rather than the underlying DPDR. For example, Louise described how the healthcare professionals she met didn't know how to treat DPDR and suggested tackling the low mood and anxiety with the hope that it would improve the DPDR. Hamilton explained how his psychiatrist googled what medication to give him for DPDR.

> "…he was just literally like bringing up like googled studies" (Hamilton)

Where needs were not met by professionals in community mental health teams, interviewees were referred on to the specialist DPDR clinic in the UK. For some this was helpful, but even in a specialist clinic, a lack of knowledge about how to best treat DPDR still existed.

> "…I'd hoped that with how specialised it was, there might be more specialised treatment or some kind of cure…" (Louise)

NHS VS Private healthcare. In addition to the lack of knowledge about DPDR within the healthcare system, participants also described a difference between NHS and private services. One of the key differences was the waiting times for assessment and intervention which were much longer in the NHS.

> "I couldn't get seen with the NHS for 12 months" (Liam)

> "…they were kind of like, yeah, there's also … this huge waiting list" (Taylor)

> "There was a wait for kind of every step" (Louise)

In addition to the waiting list, interviewees discussed limited availability of resources to understand and treat DPDR.

> "…there's a definite, palpable sense that they don't have the resource avail… the context to be able to engage DPDR as DPDR" (Shawn)

> "…funding and resources aren't necessarily dedicated to the understanding of DPDR" (Imogen)

> "there's not many people that are specialising in [DPDR]" (Rebecca)

In contrast, participants that accessed support through private services had shorter wait times and found that their needs were more likely to be addressed. Additionally, this provided a better route to getting a diagnosis of DPDR.

> "they saw me … it wasn't too long. I think it was maybe a week or two…" (Liam)

> "I then had to go and see somebody privately to actually get help for the dissociation" (Rebecca)

> “…right now I’m getting the help I need and … I’m lucky I can afford that.” (Taylor)

Theme 5: The impact of limited knowledge and understanding of DPDR

The impact of a limited knowledge, understanding and awareness of DPDR from healthcare professionals, family and friends was another theme that was present throughout the interviews. Interviewees described that the people around them thought they were mad or crazy due to their experience of DPDR. They discussed struggling with explaining their experiences to their family and friends and questioned why other people would understand DPDR if mental health professionals could not. This resulted in some participants keeping their DPDR experiences a secret from friends and family.

> “I talked to my mum … her reaction was very bad … like “are you crazy?” She didn’t understood” (Lourdes)

> “If many psychologists don’t understand, will people understand?” (Lourdes)

> “…how can I expect someone who’s literally never heard of this before to kind of errr grasp what I mean by it” (Lucy)

> “…nobody else had any idea what I was talking about and it was really frustrating and very invalidating” (Annie)

Hopelessness. One emerging sub-theme was hopelessness at both not understanding DPDR and there being no cure. When interventions were unsuccessful, participants described feeling hopeless. There was a sense that they would have to learn to live with this distressing feeling and that they would never be helped.

> "You almost think this is gonna fix you, or at least give you some understanding, and because it didn't do that, I was then like, …where do I go or what do I do?" (Rebecca)

> "…there's … no actual treatment like definite cure and stuff like this and so that I think added to the kind of like hopelessness a bit more…" (Louise)

Left to seek own answers. Another recurring aspect was the length that participants had gone to find their own answers to understand DPDR and this became a sub-theme. In particular, participants described how they turned to the internet to research and better understand DPDR. They had also sought out internet forums and found some understanding from online communities. However, this also had a downside as often unhelpful theories about the causes of DPDR and coping strategies were proposed.

> "I just started to Google something and then when I discovered … DPD … it was the first time, I think I was connecting with something…" (Rebecca)

> "I'm just kind of constantly having like information, or like having to educate myself more on [DPDR]" (Annie)

> "Reddit … or social media stuff is people's main means to get any answers." (Liam)

> "…the problem with it being the internet is that you get nutters constantly chipping in with some crazy theories that don't help" (Liam)

> "…the problematic forums out there are still going terrifyingly at the moment…" (Hamilton)

The value of a diagnosis. Where participants had received a diagnosis, they discussed the value of this in helping to provide understanding and self-compassion. This supported interviewees to reduce the impact of feeling mad and hopeless. Bringing understanding to their situation via a diagnosis of DPDR therefore became a strategy for managing DPDR experiences. Hence, the value of a diagnosis was the third sub-theme.

> "…absolutely liberating [to receive a diagnosis of DPDR], because it meant that I could, you know, Google my symptoms, get support and then eventually I joined a charity which supports people with DPDR" (Imogen)

> "[A diagnosis] was a huge relief … it was some sort of answers and a path out." (Liam)

> "I suppose [a diagnosis] was the first thing that made me feel like I'm not completely crazy" (Rebecca)

> "I felt like I wasn't going crazy" (Lucy)

> "[A diagnosis was] a bit of validation … I guess it's more been for myself, like to give myself a break." (Hamilton)

However, whilst diagnoses of DPDR were generally helpful in bringing understanding to the interviewees' experiences, there were also times when a diagnosis was less useful. This was mainly linked to limited treatment resources for DPDR or a lack of awareness and acknowledgment of the diagnosis by medical professionals.

> "[a diagnosis of DPDR] also didn't suddenly give me that relief, because then you're waiting again. So, there's nobody there to actually explain it to you. It's just a letter …" (Rebecca)

> "Although [the DPDR diagnosis] on my medical records, it has literally never been brought up with me by any team I've had since. It's like completely been ignored." (Lucy)

> "...because [the DPDR diagnosis is] not recognised, it doesn't particularly make a difference to, I guess most of my life" (Lucy)

Theme 6: Expectations of the healthcare system

Towards the end of the interview, participants were asked about their hopes for themselves and others seeking help for DPDR from the healthcare system in the future. They outlined different expectations, such as being treated as an individual with a whole story and increasing time, resources and more specialist services.

> "…if more was invested kind of earlier to assess and properly look at me as a whole…" (Taylor)

> "having that time to just listen to someone's story a bit" (Shawn)

> "…you don't have to be on waiting lists for the well-known centre in the UK for depersonalisation derealisation disorder…" (Rebecca)

Help available when asking. Of particular note was participant's hope that there would be immediate help available for DPDR when people sought help. Additionally, participants described how there needed to be better processes in place so that people asking for help were met with a system that addressed DPDR directly.

> "…being able to be pointed towards people that do, or that could possibly understand, and that it happens just a little bit quicker…" (Rebecca)

> "I'd hope that they knew straight away that there was help out there." (Hamilton)

> "…a proper system to help people with this…" (Liam)
>
> "…some way of making that information accessible to people who have [depersonalisation and derealisation] feelings." (Louise)

More education and research. Participants reflected on their own poor experiences of seeking help through the healthcare system and being met with a meagre understanding and awareness of DPDR from healthcare professionals. As they discussed their hopes for help to be available when seeking support for DPDR, they affirmed a requirement for better education and further research into DPDR to increase understanding and awareness and create better helping systems. They also expressed that the healthcare system had a role in promoting awareness of DPDR, similarly to other mental health conditions, such as depression and anxiety. They hoped that this would help promote awareness of DPDR amongst the general population, reducing the fear and anxiety of depersonalisation and derealisation experiences. Hence more education and research became a second sub-theme.

> "that there would be like a level of understanding that I was met with rather than nothing" (Lucy)
>
> "…maybe just more in-depth research like this or maybe more publicity about it for research." (Annie)
>
> "…more campaigns that just put the word out there…" (Louise)
>
> "…I would like there to be an exploration, a desire in the NHS to want to understand dissociative disorders more … there is a wealth of knowledge that can be learned, can be researched into the disorder…" (Imogen)
>
> "…education around [DPDR] would be really good." (Hamilton)

> "…just some advancement in their education on [DPDR]." (Annie)

Consequently, an increased understanding, awareness and recognition of DPDR amongst health professionals and in wider society could help to improve the overall experience of DPDR for people experiencing this disorder.

Discussion

This study aimed to comprehensively explore a qualitative account of depersonalisation and derealisation and the subsequent experience of seeking support from the healthcare system, adding important knowledge to the field of DPDR research. It showed that DPDR is a distressing and overwhelming experience. An overarching theme was a detachment from reality, supporting the DSM-5 (APA, 2013) definition of DPDR which highlights that both depersonalisation and derealisation are "experiences of … detachment" (p.302). Participants' stories of DPDR illustrated that their experiences were often constant and impacted their senses such as sight and hearing, as well as their perception of time. These accounts also matched the DSM-5's (APA, 2013) description of DPDR which highlights the chronic nature of the disorder and the likelihood of both unusual auditory and visual experiences. Furthermore, the DSM-5 (APA, 2013) suggests that people with a diagnosis of DPDR are likely to struggle socially and functionally, another aspect that was present within the interview accounts. Yet, despite the participants' accounts matching the clinical diagnosis for DPDR and meeting the clinical cut-off on the CDS, many of the participants had struggled to obtain a clinical diagnosis of DPDR. Moreover, during the interviews, it became clear that some had not obtained an official clinical diagnosis, despite self-reporting a diagnosis. Furthermore, one participant described receiving a DPDR diagnosis privately and then having this removed from their record by the NHS. This lack of understanding and acknowledgment of the disorder appeared to further contribute to the distress and hopelessness that the participants felt. It also illustrates the complex process that people with depersonalisation and derealisation experiences have to undergo to receive a clinical diagnosis of DPDR.

The study showed that participants had generally experienced a negative journey when seeking help for DPDR. Participants described being faced with healthcare professionals who did not understand DPDR, leading to difficulties with getting a diagnosis and accessing support. Hence, lack of knowledge about DPDR emerged as a sub-theme in experience of seeking help. This limited understanding of DPDR and difficulty with getting a diagnosis supports the earlier research of Michal et al. (2016) and Loewenstein (2018), which suggested that clinicians find it difficult to diagnose DPDR due to limited knowledge of the disorder. Loewenstein (2018) suggested that people with DPDR experiences usually present as depressed and anxious and are therefore given these clinical diagnoses because depersonalisation and derealisation experiences are seen as an element of this, rather than the opposite being true. This certainly seemed to be the case for the participants in this study who discussed experiencing symptoms of anxiety and depression alongside their DPDR, often resulting in diagnoses of these conditions instead. Moreover, given that symptoms of anxiety and depression were prevalent as part of DPDR experiences for the participants, treatment with medication and therapies were subsequently focused on these symptoms rather than DPDR. Whilst the participants recognised that at times this was helpful, they also acknowledged that this did little to reduce the symptoms of DPDR, reinforcing a loss of hope in the healthcare system. Studies by Somer et al. (2013) and Halder et al. (2023) also indicate that there is not enough evidence to support the treatment of DPDR with medication and that further research should be conducted. Nevertheless, medication to reduce what seemed to be symptoms of anxiety and depression to treat DPDR was still offered and prescribed to many of the participants.

Interviewees all had similar ideas about what might help improve diagnosis and interventions for DPDR. Common sub-themes emerged about the need for help to be available when asking and more education and research. When participants reflected on their own experiences of seeking help, they recounted difficulties at even being referred to their local mental health teams. There were often stumbling blocks regarding the long waiting times and the confusion of the GP when presented with experiences of DPDR. Therefore, participants expressed that there was a need for a clear pathway for people with DPDR experiences to be referred and get support quickly. Additionally, participants discussed the terrifying nature of DPDR and being without help as increasing the fear and isolation that the condition was triggering. Consequently, they believed that creating a more effective pathway to getting help for DPDR could reduce the intensity of the depersonalisation and derealisation experiences and further promote recovery. This also linked with the importance of increasing education and research about DPDR in healthcare, as participants highlighted that to signpost to appropriate help, clinicians needed to further recognise experiences of DPDR and better understand the condition.

Theoretical and aetiological aspects

Existing theories of DPDR suggest that biopsychosocial factors interact with each other to trigger the disorder (Murphy, 2023). An early model by Sierra & Berrios (1998) proposed that “the state of increased alertness observed in depersonalization results from an activation of prefrontal attentional systems … and reciprocal inhibition of the anterior cingulate” (p. 898). Subsequent research has supported these findings of a neurobiological link with DPDR (Phillips & Sierra, 2003 & Lemche et al., 2008) in response to emotion. An environmental factor shown to trigger depersonalisation and derealisation experiences is cannabis use (Simeon et al., 2009; Heugten-Van der Kloet et al., 2015 & Madden & Einhorn, 2018). Some of the participants in the current study had also engaged in cannabis use which precipitated DPDR, supporting these theoretical findings. Finally, psychological causes include anxiety and depression as already discussed, and childhood trauma, particularly emotional abuse (Simeon et al., 2001 & King et al., 2020). The brain and body's frequent exposure to these psychological experiences subsequently triggers changes in the brain which result in depersonalisation and derealisation (Saini et al., 2022). This may also be the case for cannabis use which potentially is altering the brain's response. Less literature exists for the link between trauma not related to abuse and later DPDR. In the current study participants discussed other types of trauma related to medical and religious settings, which were not specifically abuse. This suggests that there could be other types of trauma which are associated with DPDR. This type of trauma may result in similar biological changes to childhood abuse and increase the risk of environmental factors, such as cannabis use. Consequently, other types of trauma and their associations with depersonalisation and derealisation experiences should be explored in further research as this may enhance the theoretical understanding of DPDR.

Strengths and Limitations

Vasileiou et al. (2018) affirms that in qualitative research, sample size should be decided by details relating to epistemology, methodology and practicality. In the case of this study, the sample size was determined by both methodology and practicality, as the sample was only available from those who had provided contact details at the end of the survey. Once these participants had been contacted and some had been excluded due to not responding to the request to an interview or no longer being able to take part, a final sample size of 10 was determined. However, Hennink and Kaiser (2022) found that there is important evidence that counters the claim of qualitative sample sizes that are small. Lincoln & Guba (1985) propose that sampling involved in naturalistic inquiry via qualitative research aims to reach informational saturation rather than to focus on the generalisability of the results. In a systematic review of empirical tests, Hennink and Kaiser (2022) found that on average it takes between 9 and 17 interviews to reach this data saturation point. Saunders et al. (2017) affirm that data saturation is reached “when the researcher begins to hear the same comments again and again” (p.1896), in addition to an absence of new perspectives being offered. In the case of this study, which had 10 interviews, landing within the range of Hennink and Kaiser’s (2022) study, data saturation was achieved using Saunders et al.’s (2017) definition. Consequently, the findings of this study are indicative of what might be found in similar studies of this nature, suggesting good external validity.

The characteristics of the sampled participants were also important to consider. The majority of the participants interviewed were female, in line with Campbell’s (2021) assertion that females are likely to experience DPDR at double the rate of men. Yet, Wilkhoo et al. (2024) found that DPDR is experienced equally by both males and females, suggesting that the rate of female participants in this study may have been skewed. Despite this, Seedat et al. (2009) found “that women have a significantly higher lifetime risk than men of most mood disorders … and all anxiety disorders” (p.789). Given that this study found a strong connection between depression and anxiety with DPDR, Seedat et al.’s (2009) findings may also account for the possible higher rate of female participants in this study.

Participants were mostly based in the United Kingdom (UK) and mainly identified as ethnically white. This may have also reflected the higher prevalence rate of DPDR that is present in the United Kingdom (Wilkhoo et al., 2024). Furthermore, the majority white identifying sample may have reflected the UK population, as the 2021 UK census indicated that 81.7% of people across England and Wales identified within the “White” ethnic group (Garlick, 2022). Yet, a mostly white identifying sample from the UK fails to consider nuances within cultural experiences of DPDR. Although a minority identified as from a mixed ethnic background, and some participants were from outside of the UK, it does not speak to experiences of other minority ethnic backgrounds, which may have different experiences of both DPDR and accessing support within a healthcare system. Consequently, further research should be conducted to ensure that minority voices are also heard and can inform research about DPDR experiences.

Another area to be considered in future research is how the DPDR diagnosis is defined. The study had initially aimed to recruit participants with a diagnosis of DPDR. Whilst all participants had first-hand experience of depersonalisation and derealisation, not all had received a clinical diagnosis. Additionally, one participant had the DPDR diagnosis removed from their NHS record against their will. Moreover, other participants were confused about whether they had received a diagnosis, explaining that they had been informed verbally or by letter but not had it confirmed, whilst others had just come across the diagnosis on their NHS record. This may reflect the issues with diagnosis of DPDR as described by Michal et al. (2016) and Loewenstein (2018). Given the small participant sample available and the difficulty with diagnosis, the researcher made the decision to continue with the interviews where individuals disclosed that they did not have a formal diagnosis of DPDR, as this could still provide important information. Yet, without a clinical diagnosis, it is difficult to draw formal conclusions about DPDR as a clinical disorder. Nevertheless, regardless of a formal diagnosis, all participants had met the clinical cut off of 70 on the Cambridge Depersonalisation Scale (CDS) indicating the presence of DPDR and so similarities between their responses could be explored further.

According to McGrath et al. (2018), interviews in qualitative medical research are a common and appropriate tool for collecting data. Semi-structured interviews are exploratory in nature and help to gather rich data on a selected topic (Magaldi & Berler, 2020). They are an opportunity to investigate subjects which are personal to a particular group in great depth (Adams, 2015), hence were appropriate for investigating individual experiences of DPDR. DiCicco-Bloom and Crabtree (2006) recommend that semi-structured interviewers use “open, direct, verbal questions … to elicit detailed narratives and stories” (p.317). The interview guide was carefully developed to consider the type of question and order of questions to ensure that data gathered was rich in nature. The interview guide was structured around the phases of interview (as detailed in the methodology section) proposed by Whiting (2008), which suggests how questions should be ordered to put participants at ease and enrich discussion. Additionally, initial data analysis is expected to take place during data collection, hence interview questions can be adapted and changed based on preliminary findings and the interviewer’s increased understanding of the topic (DiCicco-Bloom & Crabtree, 2006). In the case of this study, the interviewer started to notice new topics of exploration such as neurodiversity and the effect of DPDR on participants’ vision. Consequently, the interviewer followed DiCicco-Bloom and Crabtree’s (2006) advice and ensured that new interview questions were added to capture these experiences. This proved to be useful as new ideas and themes were uncovered which appeared central to the understanding of the DPDR experience. Thus, the semi-structured interview method was a strength of this study, which allowed rich data to be obtained from participants and new ideas and understandings to be explored in depth.

In this study, the coding for the thematic analysis approach was conducted by one person. Turner (2020) asserts that only using one coder reduces the reliability and validity of the thematic analysis method. This study therefore was unable to benefit from the good practice of intercoder reliability (O’Connor & Joffe, 2020). However, McDonald et al. (2019) and Braun and Clarke (2019) highlight that successful coding is about how the researcher reflects on the data they are interpreting and the codes that are induced. In this case, the interviewer also conducted the thematic analysis. This meant that there was an opportunity to become familiar with the data at all steps of the process, beginning with the development of the interview questions. This allowed the interviewer to reflect on how the interview questions were meeting the overall research questions and facilitated adaption of the questions when common topics began to appear. Following completion of the interviews, the researcher had an opportunity to appraise all the transcripts and immerse in the data, prior to coding. This facilitated the researcher in generating codes that were relevant to the research questions. Additionally, as a last step in the process, to reduce researcher bias, the anonymised interview transcripts, codes and themes were shared with the researcher's supervisor for final comments on the findings. This process helped to increase the reliability and validity of the findings.

Implications

Research

An important observation from the qualitative data was the participants who identified as neurodivergent. Even those who did not have a diagnosis of neurodivergence, discussed exploring or wanting to explore the possibility of an autism or Attention Deficit Hyperactivity Disorder (ADHD) diagnosis due to exhibiting traits of these conditions. This suggested that neurodivergence may play a role in the development and expression of depersonalisation and derealisation experiences. There is already evidence that developmental trauma and neurodiversity may be related. For example, Kirby (2024) explains that developmental trauma and neurodiversity can interrupt the development of important processes including executive functioning and the regulation of emotion and attachment, making it difficult to differentiate between the two experiences. Additionally, there is evidence of a higher risk of having experienced trauma for people with autism and ADHD (Lobregt-van Buuren et al., 2021 &

Marples, 2023). Given that people who have experienced DPDR are more likely to have experienced developmental trauma, this may help to explain why neurodivergence is more likely to present itself in this group of people. Alternatively, some participants also discussed struggling with their sense of self. A limited sense of self has already been shown to be a feature in experiences of DPDR (Lassri et al., 2022). Children with diagnoses of autism and ADHD have also shown lower levels of self-esteem than their typically developing peers (Van der Cruijsen & Boyer, 2021 & Sürig et al., 2024). Therefore, it is possible that individuals with neurodivergent traits may be more likely to experience low self-concept clarity, hence why they may be increasingly susceptible to developing DPDR. Moreover, the studies by Wong et al. (2019) and Baroncelli et al. (2025) evidencing a relationship between childhood trauma and lower self-concept clarity, may also provide some explanation as to why those who are neurodivergent with a background of trauma are more likely to develop DPDR. Consequently, the role of neurodiversity in DPDR experiences is an important area for future research.

In addition to neurodiversity being a possible important aspect of DPDR, the sub-theme ‘all encompassing nature’ highlighted the role of the senses in depersonalisation and derealisation experiences, in particular sight. Multiple participants discussed difficulties with their eyesight when experiencing DPDR, to the extent that some even attended the optician to check out their concerns. This supported earlier research by Baker et al. (2003) which found that one of the most common difficulties when experiencing depersonalisation and derealisation are visual disturbances, such as seeing the world as two dimensional. The participants in the current research used similar descriptions to participants in Baker et al’s. (2003) study, depicting the world as flat and cartoon like. Michal et al. (2006) has also discovered a link between perceived visual impairment and DPDR, going so far as to suggest that ophthalmologist’s should consider DPDR as a differential diagnosis when there is no clinical reason for visual impairment. Furthermore, Lambert, Senior, Phillips, et al., (2001) found that DPDR "correlated with impaired ability to generate visual images" (Lambert, Senior, Phillips, et al., 2001, p.259). Moreover, they highlighted that this ability was more affected when generating images of other people and the self, rather than objects, suggesting that self-concept clarity may also impact visual perception in addition to cognitive aspects. Yet, despite these early pieces of research evidencing the importance of visual perception in DPDR experiences, little literature exists about the role this plays in DPDR experiences. Consequently, further studies should be conducted to explore how and why visual perception affects depersonalisation and derealisation.

Clinical

Talking therapies are a frequently proposed treatment for dissociative disorders (NHS, 2023). In particular, CBT has the strongest evidence base for treating DPDR (Meteyard, 2022) and has demonstrated some effectiveness in reducing clinical experiences of depersonalisation and derealisation (Hunter et al., 2023 & Farrelly et al., 2024). In this study, participants commonly received a Cognitive Behavioural Therapy (CBT) intervention, in line with this evidence base and guidance. Yet, the quality and quantity of existing research into treatments for DPDR is poor (Wang et al., 2024). Furthermore, studies do not exist into the effectiveness of other psychological interventions. Another psychological intervention which may be more suitable as a therapy for DPDR is Acceptance and Commitment Therapy (ACT). ACT devolved from cognitive behavioural therapy as a third wave approach and accentuates the importance of acceptance of challenging thoughts and feelings (Glasofer, 2024). Two of the themes generated from the thematic analysis (Experience of seeking help & The impact of knowledge and understanding of DPDR) emphasise a sense of depersonalisation and derealisation experiences not being understood or accepted. Although this is most prevalent in these two themes, it is an idea that was present amongst all the themes, reinforcing the detachment from reality, playing an underlying role in the maintenance of DPDR and a possible factor in why DPDR, anxiety and depression were so interconnected and confused. When participants spoke about what it meant to receive a diagnosis, they described being understood as a way of accepting their experiences. They expressed that once they accepted these experiences, the very nature of the depersonalisation and derealisation appeared to reduce, highlighting the importance of acceptance. Consequently, if acceptance was a key factor in reducing distress, an ACT intervention which holds acceptance at the very core of the approach, should be supportive in reducing the intensity of DPDR.

In addition to psychological interventions, medical interventions should also be reviewed. Wang et al. (2024) suggests that medication is the most common intervention for DPDR. Yet, the UK National Institute of Health and Care Excellence (NICE) guidelines do not propose any specific medications to address DPDR (Meteyard, 2022). This highlights the confusion between research and guidelines for DPDR and perhaps contributed to healthcare professionals' lack of knowledge about DPDR when participants sought help. The research that does exist regarding medical interventions has shown to be inconclusive (Somer et al., 2013). For instance, a systematic review of evidence-based treatments for DPDR by Somer et al. (2013) found that Lamotrigine was effective in one study but not in another, whilst Fluoxetine showed no effect at all. Despite this confusion over the efficacy of medication to treat DPDR, most of the participants had been prescribed some form of antidepressant medication. Some participants expressed that when this treatment wasn’t successful, their sense of hopelessness at having no cure for DPDR was reinforced, as shown in the sub-theme of hopelessness. Given this experience, it is important for healthcare professionals to review their use of medication to treat DPDR, as this may be further maintaining depersonalisation and derealisation experiences.

Another practical implication of the findings was participants' experience of seeking help. Participants described being met by healthcare professionals who did not understand their experiences, often misattributed the difficulties to other diagnoses and poor systems which had long waiting lists and limited resources. As a consequence, participants described feeling invalidated, hopeless and abandoned. The language participants used to express how they felt seemed to mirror the language used to depict how they felt during their early childhood trauma experiences. It appeared that the healthcare professionals and systems were replaying some of the traumatic relationships that participants had experienced during childhood. Given the established link between childhood trauma and DPDR, people with these experiences are likely to be more at risk of being excluded from healthcare support due to a lack of sensitivity and compassion about their traumatic life experiences (Fenney, 2019). Consequently, to avoid being met by a system that causes re-traumatisation, the healthcare system and professionals should look to adopt trauma informed practice. According to the Office for Health Improvement & Disparities (2022) trauma informed practice involves considering six important factors: collaboration, trust, culture, safety, empowerment and choice. It is essential for people experiencing depersonalisation and derealisation to attend services where their experiences are validated, helping them to know that they are safe to talk about their experiences and that professionals can be trusted to offer support and sit with their distress. Moreover, it is important for people with DPDR to work alongside health professionals in developing a treatment plan that aligns with their needs, providing control and autonomy in their recovery. Adopting a trauma-informed care approach can help to reduce the possibility of re-traumatisation and foster trust in healthcare professionals and systems (Sweeney et al., 2018), leading to better overall health outcomes for DPDR.

Conclusion

This qualitative study indicates that DPDR is an all-consuming experience which causes a sense of detachment from oneself and the world leading to high levels of distress. It is clearly a complex disorder making the diagnosis process challenging. So far, limited research and education has meant that there is not enough understanding of the complexities of the disorder, such as how the disorder is experienced, causes, maintaining factors and treatment. The poor understanding of DPDR as a disorder has led to individuals experiencing DPDR not receiving a diagnosis and subsequent appropriate support that might help in alleviating the symptoms of depersonalisation and derealisation. Moreover, some individuals who are likely to meet the criteria for DPDR are offered other diagnostic labels such as depression and anxiety, invalidating their experiences and further contributing to high levels of distress. This results in a sense of hopelessness about the possibility of being cured and a desire to seek answers from peers online rather than professionals. Consequently, it is important that a clearer criterion for DPDR diagnosis is established that accounts for its interconnection with anxiety and depression. Furthermore, research should focus on causes, maintaining factors and efficacy of treatment for DPDR, as well as explore new possible treatment approaches. Moreover this study highlights the similarities between experiences of depersonalisation and derealisation and traits of neurodivergence, hence neurodivergent sensitive approaches should also be explored alongside interventions that address the DPDR. It is hoped that further research and increased specialist education of healthcare professionals about DPDR can help to provide a trauma-informed healthcare system that ensures support will be available for people who experience DPDR in the future.

Chapter 4

Chapter Overview

The following chapter provides an overview of the findings, making links between the findings of the quantitative and qualitative individual studies. It discusses the relationship between DPDR, depression and anxiety, the roles of religion and self-concept clarity in DPDR experiences and the role of drug use as a trigger and maintenance factor of DPDR. The discussion explores strengths and limitations of the design of the study. It then goes onto consider how the overall study contributes to the research field and theory of DPDR, before making practical suggestions about the diagnosis and treatment of DPDR. The final discussion hoped to address the research questions posed in chapter 1 (copied again here).

1. How do adverse childhood experiences affect the development of depersonalisation and derealisation?
2. Do religion and gender play a role in the relationship between adverse childhood experiences and depersonalisation and derealisation?
3. How does self-concept clarity affect experiences of depersonalisation and derealisation, including the relationship between adverse childhood experiences and depersonalisation and derealisation?
4. What first-hand accounts of depersonalisation and derealisation can people with a diagnosis of DPDR provide?
5. How do these first-hand accounts inform understanding of DPDR and potential treatment recommendations?

Final Discussion

This study was a unique opportunity to explore the journey of DPDR, from aetiological factors to experiences of depersonalisation and derealisation to diagnosis to treatment, from a quantitative and qualitative perspective. In addition to thoroughly exploring DPDR, the quantitative and qualitative studies both explored participants' experiences of anxiety and depression. In the quantitative study, the overall sample reported clinically significant levels of anxiety and depression as well as DPDR. Furthermore, experience of adverse childhood events increased the likelihood of them experiencing anxiety and depression. Moreover, a higher sense of self-concept clarity appeared associated not just with lower DPDR but also with lower scores on measures of anxiety and depression. The qualitative study subsequently established a theme of the 'interconnected nature of anxiety, depression and DPDR', providing a richer understanding of these quantitative results. Participants described how anxiety and depression were present alongside symptoms of DPDR or presented similarly. Anxiety was considered to be both a trigger and maintenance factor for DPDR. Additionally, participants discussed how they were likely to score highly on typical outcome measures for anxiety and depression, despite the function of their symptoms being different. This may help to explain the observed high scores on the outcome measures for anxiety and depression in the quantitative study. For example, participants talked about the question on the PHQ-8 regarding little interest or pleasure in doing things and discussed how this was related to the sense of being detached from their body and feeling numb. Consequently, the detachment from reality rendered them unable to feel interest or pleasure from activities or events. Hence, it is important to explore responses on outcome measures for depression and anxiety to better understand the thoughts and feelings associated with each statement.

Another key finding across both studies was the role that religion plays in DPDR. The quantitative investigation established that religious or spiritual experiences can influence depersonalisation for people who have been exposed to physical, sexual or familial emotional abuse. Meanwhile, the qualitative study discovered that religion was sometimes a perpetrator of abusive experiences that may have led to DPDR. Schumaker (1995) posited that all religions have methods which create a susceptibility to dissociative experiences, supporting the idea that religion could be an aetiological factor for dissociation. In support of Schumaker's (1995) theory, Breslin and Lewis (2015) demonstrated a relationship between religious experience and scores on the Dissociative Experiences Scale (DES). However, in the quantitative and qualitative components of this study, religion also appeared to act as a protective factor reducing the impact of DPDR. In the qualitative study, participants talked about religion and a relationship with God helping to keep them grounded in the present and develop a sense of self within religion. Meanwhile the quantitative study found that the lowest CDS scores were correlated with participants who identified as being religious. Schumaker (1995) asserts that religion is one of the "major mental strategies to regulate reality and thereby safeguard us from the expanding powers of our brains" (p.35), perhaps explaining these observed results. Supporting this idea, a study by Reinert et al. (2015) found that the effect of childhood trauma on mental health was mitigated by religiosity. Therefore, future research might wish to examine the severity of childhood traumatic experiences in relation to depersonalisation and derealisation experiences and religious faith or spirituality. In support of Schumaker's theory that dissociative experiences are both caused by religion and a protective factor, a study by Demmrich et al. (2013) found that depersonalisation was greater when religious traditions were valued but not performed. Furthermore, a positive image of God lessened the association between significant religious rituals and depersonalisation experiences (Demmrich et al., 2013). Despite this evidence, there has been little research into the relationship between religion and DPDR and its function as both a causal and protective factor. Moreover, whilst this study does evidence that religion plays a role in depersonalisation and derealisation experiences, it does not indicate if there is a specific type of religion which may be more likely to play a causal or maintaining role in DPDR or a protective factor against DPDR. Therefore, future research should explore DPDR experiences in participants of different faiths.

A further interesting finding in the qualitative study was the role of drug use as a trigger and maintenance factor for DPDR. Drug use was not explored in the quantitative study; however, associations were found between childhood emotional abuse, emotional neglect and physical neglect with depersonalisation scores on the Cambridge Depersonalisation Scale (CDS). A previous retrospective cohort study by Dube et al. (2003) of over 8000 American adults found that adverse childhood experience scores were significantly related to drug use and addiction (Dube et al., 2003). Moreover, 7% of participants who had experienced childhood emotional abuse started using illicit drugs at approximately the age of 14 which was slightly greater than approximately 5% of participants with experience of sexual or physical abuse (Dube et al., 2003). These findings were later supported by Junglen et al. (2019) who found a significant association with emotional abuse in two separate studies. Similarly, Kurtulus and Elemo (2023) discovered a significant positive correlation between substance abuse, including drug use and childhood emotional neglect. Meanwhile, Schimmenti et al. (2022) observed a relationship between substance misuse and adverse childhood experiences, primarily neglect. Given that drug use is evidently associated with adverse childhood experiences, particularly the factors which showed a relationship with DPDR, and was also discussed as a trigger and maintaining factor for DPDR, it is possible that drug use is a moderaing factor between adverse childhood experiences and DPDR. An explanation for this relationship is that people who have been exposed to adverse childhood experiences may be more likely to self-medicate by using substances to help reduce their distress associated with the trauma (Emamzadeh, 2023). Moreover, Schimmenti et al. (2022) highlighted that people with exposure to different types of abuse chose to engage with different substances. For example, those who had experienced childhood physical or emotional abuse selected drugs with sedating effects such as heroin, whereas sexual abuse survivors preferred stimulant drugs such as methamphetamine. Therefore, future research that investigates the role of drug use in DPDR should explore this possible moderating relationship further and whether this is associated with specific substances.

The quantitative and qualitative study also identified the important role of self-concept clarity. In the quantitative study self-concept clarity was found to mediate the relationship between childhood emotional abuse, emotional neglect and physical neglect with DPDR. This meant that individuals with exposure to these types of childhood experiences were likely to have a reduced sense of self which then appeared to increase the individual's susceptibility to DPDR experiences. The qualitative study subsequently helped to make sense of these findings further. Participants discussed how early abuse experiences had created confusion whilst developing their identity and often resulted in negative feelings about the self. Additionally, some participants described how they did not value their needs and saw themselves as belonging to the abuser. The very nature of DPDR also affected the sense of self further. For example, DPDR experiences provided an opportunity to disconnect from the self and those negative feelings. For participants who had overcome DPDR experiences, they expressed how they had learnt to find a new sense of self through religion, therapy and learning to understand DPDR. Finding this sense of self helped with reconnecting to the world and reducing feelings of depersonalisation and derealisation. This supports Lassri et al's. (2022) finding that self-concept clarity does help to diminish depersonalisation and derealisation experiences.

However, this finding also indicates that even when experiencing DPDR, a sense of self can be developed which can help to combat DPDR itself. Therefore, developing a sense of self within the context of DPDR should be considered in treatment to alleviate DPDR experiences.

Strengths and Limitations

This overall research used a mixed methodology, employing both a quantitative study and a qualitative study. Specifically, the researcher utilised an explanatory sequential design, collecting the quantitative data prior to the qualitative data so that the qualitative study could provide further information about the observed quantitative results (Dovetail Editorial Team, 2023). This was a strength of the study as the method provided a comprehensive understanding of the phenomenon being studied (Wasti et al., 2022). The quantitative study helped to provide information about relationships between etiological factors and DPDR, whilst the qualitative study could provide a qualitative understanding of why certain patterns and relationships had been observed (Paterra, 2024). Additionally, another strength of a mixed methods approach is the use of triangulation to integrate quantitative and qualitative data (Alele & Malau-Aduli, 2023). Triangulation is “the process of using multiple methods, data sources, or perspectives to gain a more comprehensive understanding of a research problem (Alele & Malau-Aduli, 2023, Triangulation of Data, para. 1). This research investigated DPDR from different perspectives through the use of quantitative and qualitative methods and data collection methods to explore the research questions and aims in a thorough manner. Triangulating the data obtained provided further support for the findings as it illuminated these different perspectives on DPDR and helped to explain complex findings. For example, the quantitative study observed a potential mediating role of self-concept clarity on DPDR but the qualitative study was required to discover why this was possibly mediating the relationship. Given the complexities of DPDR and the limited research available into this phenomenon, a mixed method approach has therefore enabled this study to answer the research question in a more comprehensive and innovative manner (Tariq & Woodman, 2013), making a significant contribution to the field of literature already available.

However, whilst a mixed methods approach is a strength, it also has its limitations. For example, utilising a mixed methods design is time consuming, including more than one stage of collection and different data analysis (Wasti et al., 2022), as was the case in this study. A consequence of these challenges is that there was a significant gap between participant recruitment for the quantitative and qualitative study. For some participants, they had responded to the questionnaire over a year earlier, before being contacted to participate in the qualitative study. This meant that some participants were no longer willing to participate in the qualitative study whilst for others it was no longer appropriate for them to take part due to a deterioration in their DPDR. This did subsequently affect participant recruitment for the qualitative study. Moreover, having a significant gap between participant recruitment for the quantitative and qualitative studies meant that some participants were experiencing their DPDR differently or had subsequently had access to diagnosis and treatment for DPDR. Consequently, they may have been thinking about their DPDR experiences from a different perspective to the information they provided during the quantitative part of the study. Therefore, this may have impacted the usefulness of the data collected.

In addition to a mixed methods approach being resource heavy and time consuming, Alele and Malau-Aduli (2023) highlight the importance of considering trustworthiness and rigour. Trustworthiness and rigour is how researchers show that their research is of high quality (Ayton, 2023). Quantitative and qualitative studies differ in the language and method of assessing trustworthiness and rigour. For example, quantitative studies use terms such as reliability, validity and generalisability which look at the consistency and accuracy of the results and how this can be applied to a larger and broader sample of people (Ayton, 2023). Meanwhile, qualitative studies use language such as dependability, credibility and transferability, which although broadly mean the same as the quantitative terms detailed, assess these concepts through qualitative means such as audit trails rather than quantitative tools such as statistical analysis (Ayton, 2023). It is important that the quality of quantitative and qualitative studies are assessed differently because what might be unhelpful in one type of study can be useful in another. For example, quantitative researchers do not want confounding variables such as human emotion in their research whilst for qualitative researchers, this can often be extremely valuable (Leung, 2015). However, trustworthiness and rigour is difficult in mixed-methods research because the overall rigour of the quantitative and qualitative components of the study should be appraised together to assess integration of data (Alele & Malau-Aduli, 2023; Lorenzini et al., 2024). Yet, the same appraisal methods of the two components cannot be used. Moreover, as demonstrated in this study, the quantitative and qualitative components adopted different ontological and epistemological positions which shaped how the research questions and aims were designed and how the data was collected and interpreted. Whilst the researcher could increase the trustworthiness in their findings by choosing appropriate sampling, data collection and analysis methods, relevant to the ontological and epistemological positions, a full assessment of the trustworthiness and rigour of the overall study was not conducted with any validated tool as advised by Lorenzini et al. (2024). Therefore, whilst the individual studies may have been of high quality, it is more challenging to assess the quality of the integrated data from the two studies and how trustworthy it was in addressing the overall research aims.

Implications

Research

DPDR is a recognised part of symptomology for both anxiety and mood disorders (Simeon & Stein, 2024). For example, Schlax et al. (2020) found that “symptoms of [DPDR] are independent risk factors for the persistence of incidence of elevated symptoms of depression/anxiety” (p.41). Meanwhile, as already discussed, research has observed that depersonalisation and derealisation are often comorbidities of anxiety and depression (Wilkhoo et al., 2024). The current study further supports this finding. Yet, there is no clear epidemiological evidence demonstrating the relationship between DPDR, anxiety and mood disorders (Simeon & Stein, 2024). Whilst the findings from this study continue to be unable to provide a clear epidemiological relationship, they do provide quantitative and qualitative evidence, in line with previous studies, that there is a relationship between DPDR and anxiety and mood disorders. Consequently, further research focusing more on the epidemiological relationship between DPDR, anxiety and mood disorders would be pertinent.

Some methodological issues existed in the quantitative study regarding the mediation analysis directionality, as the study did not evidence that DPDR does not influence self-concept clarity. Nevertheless, the study was in line with existing research, showing that self-concept clarity is related to both adverse childhood experiences and DPDR. Furthermore, the qualitative study built on these ideas, with the perception of self and identity emerging as a sub-theme. Given that perception of self or self-concept appears to be important as indicated by both the quantitative and qualitative findings, further exploration of this factor is warranted. In particular, it may be useful to conduct further mediation analyses to explore if the results reported in this study are replicated. However, to conduct another mediation analysis, it is important to meet the assumptions and establish directionality of self-concept clarity. This can be achieved through longitudinal studies which can track individuals over time to clarify the temporal relationship between adverse childhood experiences, self-concept clarity and DPDR onset. By understanding more about the potential role of self-concept clarity in depersonalisation/derealisation experience, further studies may also wish to explore how self-concept clarity develops in individuals with depersonalisation/derealisation experiences, whether self-concept clarity can be modified through therapeutic interventions and if this subsequently reduces depersonalisation/derealisation experiences.

Theoretical

The overall study provides support for Hunter's cognitive model of DPDR (Hunter et al., 2003). Participants in the qualitative study discussed triggers and maintenance factors of their DPDR, such as social avoidance and safety behaviours, aligning with the maintenance cycle in the cognitive model. Participants discussed how DPDR was a trauma in itself and catastrophised the experience. Participants who were no longer experiencing chronic DPDR described how they had learnt to re-engage in social relationships. Furthermore, a diagnosis had helped to reduce their felt sense of being mad, consequently reducing the anxiety that they were experiencing because of DPDR and alleviating the need to engage in safety behaviours. These qualitative descriptions suggest that the cognitive model of DPDR is a helpful way of understanding and talking about DPDR.

This study also established that perception of the self plays an important role in DPDR, namely as a protective factor. High self-concept clarity resulted in lower levels of DPDR. Additionally, the sub-theme "all encompassing nature" in the qualitative study, highlighted impairment of the senses, including sight and hearing as a key part in reinforcing DPDR and the sense of detachment. The senses such as smell, touch, sight, proprioception and interoception can unconsciously ground us in reality (Ciaunica, Roepstorff et al., 2021).

Ciaunica, Roepstorff et al. (2021) found that when the sense of touch is impaired people lose the connection between the self and the body and a physical connection with the world increasing the risk of depersonalisation and derealisation experiences. Building on this theory, it is possible that impairment of other senses as discussed by the participants in the current study is reducing the physical connection to the world and increasing experiences of depersonalisation and derealisation. It is therefore essential to focus on the connection to the world by engaging all the senses rather than focusing on the disconnection to reduce DPDR experiences (Ciaunica et al., 2022). Some of the participants in the qualitative study had been advised to reconnect with the world and had found this helpful as a strategy in alleviating DPDR. Therefore, the theory that when sensory perception is impaired, the connection between the bodily sense of self and the world is affected and sometimes lost, increasing depersonalisation and derealisation experiences, should be explored further in future research, as another potential mechanism in the onset and maintenance of DPDR.

Clinical

An intervention that could be helpful in the treatment of DPDR is Cognitive Analytic Therapy (CAT) because it "[integrates] … psychoanalytic, cognitive, and constructivist ideas" (Ryle, 2005, p.196). The quantitative and qualitative studies highlighted the impact of adverse childhood experiences on the development of self-concept clarity and subsequent emotional distress later in life. For example, some of the interview participants discussed early childhood trauma and related this to a poor sense of self. CAT proposes that experiences during childhood provide a template for how people relate to themselves, the world and others (Tees, Esk and Wear Valleys NHS Foundation Trust, 2020). CAT understands the development of the self to be impacted by these relationships and patterns of cultural communication (Rafi & Prabalkumari, 2022). Consequently, CAT attempts to understand these relational patterns and how they are contributing to emotional distress. CAT may be advantageous to support those with DPDR because it can acknowledge how early developmental trauma has impacted the development of the self and influenced depersonalisation and derealisation experiences. CAT uses similar approaches to CBT, a typical and effective intervention for DPDR (Hunter et al., 2023) but is strengthened by accounting for systemic factors that may be contributing to distress. CAT has also been shown to be an effective intervention for individuals who present with complex and enduring mental health needs (Balmain et al., 2021). Yet, no studies exploring CAT as a possible intervention for DPDR exist, despite its similarities to a CBT intervention. Therefore, CAT as a differential approach to CBT should be further explored.

The overall study highlighted that clear guidance for health professionals on how to treat DPDR does not exist. As described, NICE guidelines only recognise DPDR as a symptom of other conditions (NICE, 2024; NICE 2025) rather than as a disorder to be treated separately. Moreover, there is an absence of NICE guidelines for dissociative disorders and the treatment of dissociation (Rethink Mental Illness, n.d.). NICE guidelines are intended to promote relevant treatments for specific conditions (NICE, 2003). They are developed based on research evidence and intend to ameliorate treatment for specific illnesses, disorders or conditions (NICE, 2003). Hence, even if an accurate diagnosis of DPDR could be made, clinicians were left without guidance or appropriate resources to offer treatment. Furthermore, they could not consider treatment recommendations for other dissociative disorders as no guidelines pertinent to these conditions existed. This resulted in professionals that were uncertain about the support that they recommended. The NICE (n.d.) website explains that guidelines are developed by reviewing available evidence and then conducting a literature search, followed by preparing a summary of the collected information. After this, the evidence is presented to a multi-disciplinary committee for consideration about a potential new or updated guideline (NICE, n.d.). Therefore, the researcher recommends that a new guideline for the recommended treatment of dissociative disorders, which specifically includes DPDR, is developed. This will help to improve treatment for all dissociative disorders and provide clear guidance for health professionals, creating a consistent and effective approach to treating DPDR.

Furthermore, the participants' testimony suggests that their experiences of DPDR were accepted as part of the symptomology of depression and anxiety, rather than seen as a differential diagnosis. The DSM-5 (APA, 2013) already acknowledges the co-occurring nature of DPDR alongside depression and anxiety but affirms that DPDR should be seen as independent from other mental health difficulties. Given that the quantitative study revealed that participants with DPDR also scored highly on measures for depression and anxiety, this may explain why participants in the qualitative study were diagnosed with anxiety and mood disorders but had struggled to receive a DPDR diagnosis. It is possible that this is a typical pattern for people with DPDR experiences seeking a diagnosis and therefore lots of people that do have DPDR are being misdiagnosed. Simeon & Abugel (2006) state that people with DPDR experiences are rarely offered a helpful label to describe their symptoms. Instead, health professionals inform them that they are experiencing anxiety or depression and that the DPDR symptoms are a secondary difficulty (Simeon & Abugel, 2006). This hypothesis is further supported by Perkins (2021b) who expresses that primary care services often treat DPDR with antidepressants and psychological therapy for anxiety and depression. He describes "swimming in circles in primary care before managing to progress to the experts" (Perkins, 2021b, p.108). Misdiagnosis and ineffective expert advice means that the symptoms of DPDR are not effectively treated, subsequently prolonging and potentially worsening mental health difficulties (Rigby, 2024). Duran (2021) affirms that people living with DPDR who have not received a diagnosis or experienced a misdiagnosis, are likely to believe that they are "mad".

This can subsequently impact on all areas of functioning including social relationships, family relationships and work environments (Duran, 2021). DPDR can enter a “diagnostic vacuum” meaning that typical routes to receiving a diagnosis break down and are unsuccessful (Duran, 2021). Alternatively, “diagnostic slippage” can also occur with DPDR, whereby the clinical diagnosis is no longer held and provided by medical professionals but is instead sought through independent means such as the internet, as illustrated in the qualitative component of this study (Duran, 2021). This is often because typical channels, for example via health services, have been unsuccessful in providing a clinical diagnosis due to limited expertise in the area (Duran, 2021). This indicates that there are many factors which are getting in the way of receiving a successful diagnosis and this is likely having a subsequent impact on overall functioning for people with DPDR. Consequently, a review of the diagnostic criteria for DPDR is indicated in addition to better training for health professionals to support them with making a diagnosis of DPDR and improving access to relevant and appropriate treatment.

Conclusion

This study provides a comprehensive account of what it is like to experience DPDR. It highlights factors potentially responsible for the onset and maintenance of DPDR. In particular, people who have experienced adverse childhood experiences such as emotional abuse appear more likely to be at risk of developing DPDR. However, self-concept clarity can act as a mediating factor which helps to alleviate DPDR. Self-concept clarity may be less established in people with DPDR, possibly due to abuse experiences. Additionally, characteristics of DPDR such as altered bodily perceptions and senses may further reduce the sense of self prolonging experiences of DPDR. These senses can be further affected by drug use reinforcing a sense of detachment from the self. Nevertheless, participants who found value in religion and connection to God and attempted to reconnect with the world and live their life encompassing all their senses, were more likely to increase their sense of self and connection to the world, reducing the DPDR. This suggests that a therapeutic intervention that focuses on increasing the sense of self in people with DPDR may be supportive in reducing the DPDR experiences and subsequent distress. However, further research is required to better understand self-concept clarity's role in DPDR and how this can be used to better support people living with DPDR. This study therefore advises that research continues to explore DPDR triggers and maintenance factors, in addition to protective factors that may help to alleviate DPDR.

The study also highlights that there are many issues with understanding DPDR in a clinical setting. There are no clear diagnosis criteria or treatment guidelines, resulting in people with DPDR struggling for years to obtain a diagnosis and often being misdiagnosed and unhelpfully supported by medical professionals. This likely increases distress and the chronicity of DPDR experiences. Furthermore, given the interconnected nature of anxiety and depression, it is important that this is considered within the diagnostic criteria for DPDR and not discounted as being a separate illness. Additionally, given the relationship between DPDR and traumatic experiences, medical settings should consider trauma informed practice. For example, powerful professionals and inflexible systems may re-traumatise people with DPDR who have previously experienced a lack of belief and support from adults in positions of trust and authority. Consequently, better training and education for medical professionals is required, alongside clear diagnostic criteria that takes into account cause mechanisms of DPDR and transparent guidelines for treatment. This should contribute to accurate diagnoses and effective treatment, supporting the reduction of distress that DPDR perpetuates.

References

Adams, W. C. (2015). Conducting semi-structured interviews. In K. E. Newcomer, H. P. Hatry, & J. S. Wholey (Eds.), *Handbook of practical program evaluation* (4th ed.). (pp. 492-505). Jossey-Bass. https://doi.org/10.1002/9781119171386.ch19

Aderibigbe, Y. A., Bloch, R. M., & Walker, W. R. (2001). Prevalence of depersonalization and derealization experiences in a rural population. *Social Psychiatry and Psychiatric Epidemiology, 36*(2), 63-69. https://doi.org/10.1007/s001270050291

Alele, F., & Malau-Aduli, M. (2023). *An introduction to research methods for undergraduate health profession students*. James Cook University.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing. https://doi.org/10.1176/appi.books.9780890425596

American Psychological Association. (2018). Researcher bias. In *APA dictionary of psychology.* Retrieved June 09, 2025, from https://dictionary.apa.org/researcher-bias

American Psychological Association. (n.d.). Individualism. In *APA dictionary of psychology.* Retrieved November 15, 2025, from https://dictionary.apa.org/individualism

Anderson, J. M. (1991). Reflexivity in fieldwork: toward a feminist epistemology. *Image -- the journal of nursing scholarship, 23*(2), 115-118. https://doi.org/10.1111/j.1547-5069.1991.tb00654.x

Aponte-Soto, M., Martinez-Taboas, M., Vélez-Pastrana, M. C., & González, R. A. (2019). The relationship between interpersonal abuse and depersonalization experiences. *Revista Puertorriqueña de Psicologia.* Retrieved May 16, 2025, from https://www.researchgate.net/publication/334455133_THE_RELATIONSHIP_BETWEEN_INTERPERSONAL_ABUSE_AND_DEPERSONALIZATION_EXPERIENCES_LA_RELACION_ENTRE_ABUSO_INTERPERSONAL_Y_EXPERIENCIAS_DE_DESPERSONALIZACION

Archuleta, W. P., Kaminski, P. L., & Ross, N. D. (2024). The roles of shame and poor self-concept in explaining low social connection among adult survivors of childhood emotional maltreatment. *Psychological Trauma: Theory, Research, Practice, and Policy, 16*(7), 1149-1157. https://doi.org/10.1037/tra0001559

Armour, C., Contractor, A. A., Palmieri, P. A., Elhai, J. D. (2014). Assessing latent level associations between PTSD and dissociative factors: Is depersonalization and derealization related to PTSD factors more so than alternative dissociative factors?. *Psychological Injury and Law, 7*(2), 131-142. https://doi.org/10.1007/s12207-014-9196-9

Armstrong, R. A. (2014). When to use the Bonferroni correction. *Ophthalmic and Physiological Optics, 34*(5), 502-508. https://doi.org/10.1111/opo.12131

Ayre, J., & McCaffery, K. J. (2022). Research note: Thematic analysis in qualitative research. *Journal of Psychotherapy, 68*(1), 76-79. https://doi.org/10.1016/j.jphys.2021.11.002

Ayton, D. (2023). Chapter 26: Rigour. In D. Ayton, T. Tsindos & D. Berkovic (Eds.), *Qualitative research - a practical guide for health and social care researchers and practitioners*. Monash University.

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

Balmain, N., Melia, Y., John, C., Dent, H., & Smith, K. (2021). Experiences of receiving cognitive analytic therapy for those with complex secondary care mental health difficulties. *Psychology and Psychotherapy, 94*(S1), 120-136. https://doi.org/10.1111/papt.12326

Bandini, E., Fisher, A. D., Castellini, G., Sauro, C. L., Lelli, L., Meriggiola, M. C., Casale, H., Benni, L., Ferruccio, N., Faravelli, C., Dettore, D., Maggi, M., & Ricca, V. (2013). Gender identity disorder and eating disorders: Similarities and differences in terms of body uneasiness. *The Journal of Sexual Medicine, 10*(4), 1012-1023. https://doi.org/10.1111/jsm.12062

Baroncelli, C. M. C., Lodder, P., Van der Lee, M., & Bachrach, N. (2025). The role of enmeshment and undeveloped self, subjugation and self-sacrifice in childhood trauma and attachment related problems: The relationship with self-concept clarity. *Acta Psychologica, 254*, https://doi.org/10.1016/j.actpsy.2025.104839

Bernstein, D. P., Fink, L., Handelsman, L., Foote, J., Lovejoy, M., Wenzel, K., Sapareto, E., & Ruggiero, J. (1994). Initial reliability and validity of a new retrospective measure of child abuse and neglect. *American Journal of Psychiatry, 151*(8), 1132-1136. https://doi.org/10.11/6/ajp.151.8.1132

Bernstein, D. P., & Fink, L. (1998). *Childhood Trauma Questionnaire: A retrospective self-report: Manual.* Psychological Corporation.

Bernstein, D. P., Stein, J. A., Newcomb, M. D., Walker, E., Pogge, D., Ahluvalia, T., Stokes, J., Handelsman, L., Medrano, M., Desmond, D., & Zule, W. (2003). Development and validation of a brief screening version of the Childhood Trauma Questionnaire. *Child Abuse & Neglect, 27*(2), 169-190. https://doi.org/10.1016/S0145-2134(02)00541-0

Bertule, M., Sebre, S. B., & Kolesovs, A. (2021). Childhood abuse experiences, depression and dissociation symptoms in relation to suicide attempts and suicidal ideation. *Journal of Trauma & Dissociation, 22*(5), 598-614. https://doi.org/10.1080/15299732.2020.1869652

Bezzubova, E. (2012, August 19). Hardship and discontent of depersonalization. *Psychology Today.* https://www.psychologytoday.com/gb/blog/the-search-for-self/201208/hardship-and-discontent-of-depersonalization

Bezzubova, E. (2014, June 13). Depersonalization in the DSM-5. *Psychology Today*. https://www.psychologytoday.com/gb/blog/the-search-self/201406/depersonalization-in-the-dsm-5

Bhandari, P. (2022, May 04). Inductive reasoning | Types, examples, explanation. *Scribbr.* https://www.scribbr.co.uk/research-methods/inductive-reasoning-types/

Blevins, C. A., Weathers, F. W., Davis, M. T., Witte, T. K., & Domino, J. L. (2015). The posttraumatic stress disorder checklist for DSM-5 (PCL-5): Development and initial psychometric evaluation. *Journal of Traumatic Stress, 28*(6), 489-590. https://doi.org/10.1002/jts.22059

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

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Breslin, M. J., & Lewis, C. A. (2015). Dissociation and religiosity: The role of religious experience. *Journal of Spirituality in Mental Health, 17*(1), 26-33. https://doi.org/10.1080/19349637.2015.9576064

Brown, N. (2015, November 03). Epistemology. *Social Research & Practice and Education Ltd.* https://www.nicole-brown.co.uk/epistemology/#:~:text=Pietroortolani%20says:-,at,made%20clear%20from%20the%20beginning.

Byrne, D. (2022). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & Quantity, 56*, 1391-1421. https://doi.org/10.1007/s11135-021-01182-y

Campbell, J. D., Trapnell, P. D., Heine, S. J., Katz, I. M., Lavallee, L. F., & Lehman, D. R. (1996). Self-concept clarity: Measurement, personality correlates, and cultural boundaries. *Journal of Personality and Social Psychology, 70*(1), 141-156. https://doi.org/10.1037/0022-3514.70.1.141

Campbell, M., McKenzie, J. E., Sowden, A., Katikireddi, S. V., Brennan, S. E., Ellis, S., Hartmann-Boyce, J., Ryan, R., Shepperd, S., Thomas, J., Welch, V., & Thomson, H. (2020). Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. *The BMJ,* https://doi.org/10.1136/bmj.l6890

Campbell, L. (2021, August 9). *All about depersonalization/derealization disorder.* Psych Central. https://psychcentral.com/disorders/depersonalization-derealization-disorder

Canan, F., & North, C. S. (2019). Dissociation and disasters: A systematic review. *World Journal of Psychiatry, 9*(6), 83-98. https://doi.org/10.5498/wjp.v9.i6.83

Carlson, E. B., & Putnam, F. W. (1993). An update on the Dissociative Experiences Scale. *Dissociation: Progress in the Dissociative Disorders,* Retrieved February 22, 2025, from https://www.researchgate.net/publication/232515683_An_Update_on_the_Dissociative_Experiences_Scale

Cassano, G. B., Petracca, A., Perugi, G., Toni, C., Tundo, A., & Roth, M. (1989). Derealization and panic attacks: A clinical evaluation on 150 patients with panic disorder/agoraphobia. *Comprehensive Psychiatry, 30*(1), 5-12. https://doi.org/10.1016/0010-440X(89)90112-0

Center for Disease Control and Prevention. (2024, October 08). *About adverse childhood experiences.* CDC. https://www.cdc.gov/aces/about/index.html

Center for Survivors. (n.d.). *Interpersonal violence.* Michigan State University. Retrieved May 30, 2025, from https://centerforsurvivors.msu.edu/resources/interpersonal-violence/#:~:text=Interpersonal%20violence%2C%20also%20referred%20to,Stalking%20behaviors

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), https://doi.org/10.1371/journal.pone.0247037

Černis, E., Loe, B. S., Lofthouse, K., Waite, P., Molodynski, A., Ehlers, A., & Freeman, D. (2024). Measuring dissociation across adolescence and adulthood: developing the short-form Černis Felt Sense of Anomaly scale (ČEFSA-14). *Behavioural and Cognitive Psychology, 52*, 163-177. https://doi.org/10.1017/S1352465823000498

Chang, X., Jiang, X., Mkandarwire, T., & Shen, M. (2019). Associations between adverse childhood experiences and health outcomes in adults aged 18-59 years. *PLOS One, 14*(2), https://doi.org/10.1371/journal.pone.0211850

Child completed questionnaires, (n.d.). University of Bristol. Retrieved February 06, 2023, from https://www.bristol.ac.uk/alspac/researchers/our-data/questionnaires/child-completed-questionnaires/

Chiu, C-D., Tseng, M-C. M., Chien, Y-L., Liao, S-C., Liu, C-M., Yeh, Y-Y., & Hwu, H-G. (2015). Cumulative traumatization associated with pathological dissociation in acute psychiatric inpatients. *Psychiatry Research, 230*(2), 406-412. https://doi.org/10.1016/j.psychres.2015.09.028

Ciaunica, A., Charlton, J., & Farmer, H. (2021). When the window cracks: Transparency and the fractured self in depersonalisation. *Phenomenology and the Cognitive Sciences, 20*(2), 1-19. https://doi.org/10.1007/s11097-020-09677-z

Ciaunica, A., Roepstorff, A., Fotopoulou, A. K., & Petreca, B. (2021). Whatever next and close to my self – the transparent senses and the “second skin”: Implications for the case of depersonalization. *Frontiers in Psychology, 12*, https://doi.org/10.3389/fpsyg.2021.613587

Ciaunica, A., McEllin, L., Kiverstein, J., Gallese, V., Hohwy, J., & Woźniak, M. (2022). Zoomed out: digital media use and depersonalization experiences during the COVID-19 lockdown. *Scientific Reports, 12*(1), https://doi.org/10.1038/s41598-022-07657-8

Ciaunica, A., Seth, A., Limanowski, J., Hesp, C., & Friston, K. J. (2022). I overthink–Therefore I am not: An active inference account of altered sense of self and agency in depersonalisation disorder. *Consciousness and Cognition, 101*, https://doi.org/10.1016/j.concog.2022.103320

Cleveland Clinic. (2023, September 29). *Depersonalization-Derealization Disorder.* Cleveland Clinic. https://my.clevelandclinic.org/health/diseases/9791-depersonalization-derealization-disorder

Cohen, A. B., & Hill, P. C. (2007). Religion as culture: Religious individualism and collectivism among American Catholics, Jews, and Protestants. *Journal of Personality, 75*(4), 709-742. https://doi.org/10.1111/j.1467-6494.2007.00454.x

Colizzi, M., Costa, R., & Todarello, O. (2015). Dissociative symptoms in individuals with gender dysphoria: Is the elevated prevalence real?. *Psychiatry Research, 226*(1), 173-180. https://doi.org/10.1016/j.psychres.2014.12.045

Collins, N. L. (1996). Revised Adult Attachment Scale. *APA PsycTests,* https://doi.org/10.1037/t19162-000

Corson, K., Gerrity, M. S., & Dobscha, S. K. (2004). Screening for depression and suicidality in a VA primary care setting: 2 items are better than 1 item. *American Journal of*

Managed Care. Retrieved July 14, 2025, from https://www.ajmc.com/view/nov04-1949p839-845

Coutts, J. J., Al-Kire, R. L., & Weidler, D. J. (2023). I can see (myself) clearly now: Exploring the mediating role of self-concept clarity in the association between self-compassion and indicators of well-being. *PLOS One, 18*(6), https://doi.org/10.1371/journal.pone.0286992

Davis, S (2022, February 21). Rejection trauma and the freeze/fawn response. *CPTDS Foundation.* https://cptsdfoundation.org/2022/02/21/rejection-trauma-and-the-freeze-fawn-response/

Dechalert, A. (2024, July 11). 10 advantages & challenges of thematic analysis. *Thematic.* https://getthematic.com/insights/thematic-analysis-advantages/

DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health, 7*(2), https://doi.org/10.1136/fmch-2018-000057

Demmrich, S., Wolfradt, U., & Domsgen, M. (2013). Dissociation in religion and spirituality: God images and religious rituals in the context of dissociative experiences among a sample of German adults. *Journal of empirical theology, 26*(2), 229-241. https://doi.org/10.1163/15709256-12341276

De Silva, N. (2015). *The relationship between childhood abuse and dissociation* (Publication No. 3687330) [Doctoral dissertation, Alliant International University]. ProQuest.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*(4), 314-321. https://doi.org/10.1111/j.1365-2929.2006.02418.x

Diego-Cordero, R. D., Iglesias, Romo, M., Badanta, B., Lucchetti, G., & Vega-Escaño, J. (2022). Burnout and spirituality among nurses: A scoping review. *Explore, 18*(5), 612-620. https://doi.org/10.1016/j.explore.2021.08.001

Dorahy, M. J., & Lewis, C. A. (2001). The relationship between dissociation and religiosity: An empirical evaluation of Schumaker’s Theory. *Journal for the Scientific Study of Religion, 40*(2), 143-350. https://doi.org/10.1111/0021-8294.00058

Dovetail Editorial Team. (2023, February 20). What is mixed methods research?. *Dovetail.* https://dovetail.com/research/mixed-methods-research/

Dube, S. R., Felitti, V. J., Dong, M., Chapman, D. P., Giles, W. H., & Anda, R. F. (2003). Childhood abuse, neglect, and household dysfunction and the risk of illicit drug use: the adverse childhood experiences study. *The Journal of Pediatrics, 111*(3), 564-572. https://doi.org/10.1542/peds.111.3.564

Dunstan, S. (2025). *'Is there a relationship between Childhood Sexual Abuse (CSA) and depersonalisation and derealisation experiences in adulthood?: A systematic review'*. PsyArXiv. https://doi.org/10.31234/osf.io/yt4r5_v1

Duran, E. (2021). Diagnostic slippage: Medical uncertainty and engaged patienthood in the case of atypical disorders. *Social Science & Medicine, 280,* https://doi.org/10.1016/j.socscimed.2021.114054

E-International Relations (2021, September 25). *Positivism, Post-Positivism and Interpretivism.* E-International Relations. https://www.e-ir.info/2021/09/25/positivism-post-positivism-and-interpretivism/#:~:text=Postpositivism%20rejects%20the%20positivist%20approach%20that%20a,the%20theories%20and%20knowledge%20that%20theorists%20develop.

Eley, A. (2017, September 26). *Depersonalisation disorder: 'I was unable to feel love'.* BBC News. https://www.bbc.co.uk/news/health-41384979

Emamzadeh, A. (2023, February 10). Why childhood abuse so often leads to drug use. *Psychology Today.* https://www.psychologytoday.com/gb/blog/finding-a-new-home/202301/research-finds-link-between-childhood-abuse-and-drug-use

Essien, E., Attoe, O. R., Anake, G., Uwah, E. E., Aigbomian, E. J., Eleazu, F., & Udofia, O. (2018). The Childhood Trauma Questionnaire: Validity, reliability and factor structure among adolescents in Calabar, Nigeria. *Nigerian Journal of Medicine, 27*(3), 252-259. https://doi.org/10.4103/1115-2613.278787

Evans, G. J., Reid, G., Preston, P., Palmier-Claus, J., & Sellwood, W. (2015). Trauma and psychosis: The mediating role of self-concept clarity and dissociation. *Psychiatry Research, 228*(3), 626-632. https://doi.org/10.1016/j.psychres.2015.04.053

Farrelly, S., Peters, E., Azis, M., David, A. S., & Hunter, E. C. M. (2024). A brief CBT intervention for depersonalisation-derealisation disorder in psychosis: Results from a feasibility randomised controlled trial. *Journal of Behavior Therapy and Experimental Psychiatry, 82*, https://doi.org/10.1016/j.jbtep.2023.101911

Felitti, V. J., Ando, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Koss, M. P., & Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *American Journal of Preventive Medicine, 14*(4), 245-258. https://doi.org/10.1016/s0749-3797(98)00017-8

Fenney, D. (2019, November 14). Tackling poor health outcomes: the role of trauma-informed care. *The King's Fund.* https://www.kingsfund.org.uk/insight-and-analysis/blogs/tackling-poor-health-outcomes-trauma-informed-care

Fink, L. A., Bernstein, D., Handelsman, L., Foote, J., & Lovejoy, M. (1995). Initial reliability and validity of the Childhood Trauma Interview: A new multidimensional measure of childhood interpersonal trauma. *The American Journal of Psychiatry, 152*(9), 1329-1335. https://doi.org/10.1176/ajp.152.9.1329

Finn, G. M., Dueñas, A. N., Kehoe, A., & Brown, M. E. L. (2022). A novice's guide to qualitative health professions education research. *Clinical and Experimental Dermatology, 47*(12), 2090-2095. https://doi.org/10.1111/ced.15381

Fisher, A. D., Castellini, G., Bandini, E., Casale, H., Fanni, E., Benni, L., Ferruccio, N., Meriggiola, M. C., Manieri, C., Gualerzi, A., Jannini, E., Oppo, A., Ricca, V., Maggi, M., & Rellini, A. H. (2014). Cross-sex hormonal treatment and body uneasiness in individuals with gender dysphoria. *The Journal of Sexual Medicine, 11*(3), 709-719. https://doi.org/10.1111/jsm.12413

Fleeman, N., & Dundar, Y. (2017). Data extraction: Where do I begin?. In A. Boland, M. G. Cherry & R. Dickson (Eds.), *Doing a systematic review: A student's guide* (pp.93-106). Sage.

Frau, C., & Corrigan, F. M. (2025). Verbal abuse, depersonalization, and the innate alarm and defensive systems: A single case illustration of treatment with deep brain reorienting. *Journal of Child & Adolescent Trauma, 18*, 11-21. https://doi.org/10.1007/s40653-024-00672-z

Frewen, P. A., Brown, M. F. D., Steuwe, C., & Lanius, R. A. (2015). Latent profile analysis and principal axis factoring of the DSM-5 dissociative subtype. *European Journal of Psychotraumatology, 6*(1), https://doi.org/10.3402/ejpt.v6.26406

Fritscher, L. (2023, December 07). What to know about DPDR (Depersonalization/Derealization disorder). *Verywell mind.* https://www.verywellmind.com/derealization-2671582

Fryer, T., & Navarrete, C. (2024). *A short guide to ontology and epistemology: (why everyone should be a realist)* (3rd ed.). WordPress.

Gallagher, I. (2023, April 04). Love of one's fate – living with depersonalisation-derealisation disorder. *Mind.* https://www.mind.org.uk/workplace/influence-and-participation-toolkit/lived-experience-newsletter/love-of-ones-fate-living-with-depersonalisationderealisation-disorder/#:~:text=This%20story%20was%20written%20by,My%20unreality%20had%20a%20name.

Garlick, S. (2022, November 29). *Ethnic group, England and Wales: Census 2021.* Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/bulletins/ethnicgroupenglandandwales/census2021

Gartlehner, G., Affengruber, L., Titscher, V., Noel-Starr, A., Dooley, G., Ballarini, N., & Kanig, F. (2020). Single-reviewer abstract screening missed 13 percent of relevant studies: a crowd-based, randomized controlled trial. *Journal of Clinical Epidemiology, 121,* 20-28. https://doi.org/10.1016/j.jclinepi.2020.01.005

Gidzgier, P., Grundmann, J., Lotzin, A., Hiller, P., Schneider, B., Driessen, M., Schaefer, M., Scherbaum. N., Hillemacher, T., & Schäfer, I. (2019). The dissociative subtype of PTSD in women with substance use disorders: Exploring symptom and exposure profiles. *Journal of Substance Abuse Treatment, 99*, 73-79. https://doi.org/10.1016/j.jsat.2019.01.004

Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in psychiatric treatment, 15*, 199-208. https://doi.org/10.1192/apt.bp.107.005264

Glasofer, D. R. (2024, January 16). What is acceptance and commitment therapy (ACT)?. *Verywell mind.* https://www.verywellmind.com/acceptance-commitment-therapy-gad-1393175

Glezakis, K., Burton, A. L., Abbott, M. J., & Norton, A. R. (2024). Self-concept clarity in social anxiety: psychometric properties and factor structure of the Self-Concept Clarity Scale in a social anxiety disorder sample. *Clinical Psychologist, 28*(2), 111-121. https://doi.org/10.1080/13284207.2024.2311104

Gillette, H. (2021, August 3). What's the link between trauma and dissociation?. *Psych Central.* https://psychcentral.com/pro/coping-with-trauma-through-dissociation

Glisson, C., & Green, P. (2006). The role of speciality mental health care in predicting child welfare and juvenile justice out-of-home placements. *Research on Social Work Practice, 16*(5), 480-490. https://doi.org/10.1177/1049731506287089

Granieri, A., Guglielmucci, F., Costanzo, A., Caretti, V., & Schimmenti, A. (2018). Trauma-related dissociation is linked with maladaptive personality functioning. *Frontiers in Psychiatry, 9*, 1-8. https://doi.org/10.3389/fpsyt.2018.00206

Grassi-Oliveira, R., Cogo-Moreira, H., Salum, G. A., Brietzke, E., Viola, T. W., Manfro, G. G., Kristensen, C. H., Arteche, A. X. (2014). Childhood Trauma Questionnaire (CTQ) in Brazilian samples of different age groups: Findings from confirmatory factor analysis. *PLOS One, 9*(1), https://doi.org/10.1371/journal.pone.0087118

Gray, M. J., Litz, B. T., Hsu, J. L., & Lombardo, T. W. (2004). Psychometric properties of the life events checklist. *Assessment, 11*(4), 330-341. https://doi.org/10.1177/1073191104269954

Haczkewicz, K. M., Shahid, S., Finnegan, H. A., Monnin, C., Cameron, C. D., & Gallant, N. L. (2024). Adverse childhood experiences (ACEs), resilience, and outcomes in older adulthood: A scoping review. *Child Abuse & Neglect.* Advance online publication. https://doi.org/10.1016/j.chiabu.2024.106864

Hagenaars, M. A., Stins, J. F., & Roelofs, K. (2012). Aversive life events enhance human freezing responses. *Journal of Experimental Psychology: General, 141*(1), 98-105. https://doi.org/10.1037/a0024211

Hajian-Tilaki, K. (2011). Sample size estimation in epidemiologic studies. *Caspian Journal of Internal Medicine.* Retrieved June 09, 2025, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3895825/pdf/cjim-2-289.pdf

Halder, A. Kundu, P. S., & Ray, S. (2023). Are antidepressants effective in treating depersonalization derealization disorder: Inference from a case series. *Telangana Journal of Psychiatry, 9*(2), 162-166. https://doi.org/10.4103/tjp.tjp_57_23

Hariri, A. G., Gulec, M. Y., Orengul, F. F. C., Sumbul, E. A., Elbay, R. Y., & Gulec, H. (2015). Dissociation in bipolar disorder: Relationships between clinical variables and childhood trauma. *Journal of Affective Disorders, 184*, 104-110. https://doi.org/10.1016/j.jad.2015.05.023

Hassan, E. (2005). Recall bias can be a threat to retrospective and prospective research designs. *The Internet Journal of Epidemiology, 3*(2), https://doi.org/10.5580/2732

Heekerens, J., Felsenheimer, A., Lebovitz, J., & Černis, E. (2025). The Černis felt sense of anomaly (ČEFSA) scale: Psychometric properties and validity of a German version. *Psychological Test Adaptation and Development, 6,* 54-68. https://doi.org/10.1027/2698-1866/a000097

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine, 292,* https://doi.org/10.1016/j.socscimed.2021.114523

Hermans, E. J., Henckens, M. J. A. G., Roelofs, K., & Fernández, G. (2013). Fear bradycardia and activation of the human periaqueductal grey. *NeuroImage, 66*, 278-287. https://doi.org/10.1016/j.neuroimage.2012.10.063

Hester, M. (2013). Who does what to whom? Gender and domestic violence perpetrators in English police records. *European Journal of Criminology, 10*(5), https://doi.org/10.1177/1477370813479078

Heugten-Van der Kloet, D. V., Giesbrecht, T., Wel, J. V., Bosker, W. M., Kuypers, K. P., Theunissen, E. L., Spronk, D. B., Verkes, R. J., Merckelbach, H., & Ramaekers, J. G. (2015). MDMA, cannabis, and cocaine produce acute dissociative symptoms. *Psychiatry research, 228*(3), 907-912. https://doi.org/10.1016/j.psychres.2015.04.028

Heydrich, L., Marillier, G., Evans, N., Seeck, M., & Banke, O. (2019). Depersonalization- and derealization-like phenomena of epileptic origin. *Annals of Clinical and Translational Neurology, 6*(9), 1739-1747. https://doi.org/10.1002/acn3.50870

Hoeboer, C. M., Bodor, N., Oprel, D. A. C., de Kleine, R. A., Schoorl, M., van Minnen, A., & van der Does, W. (2025). Validation of the Childhood Trauma Questionnaire (CTQ) in the context of Trauma-Focused Treatment. *Child Maltreatment, 0*(0), 1-12. https://doi.org/10.1177/10775595251328611

Hodgson, R. C., & Webster, R. A. (2011). Mediating role of peritraumatic dissociation and depression on post-MVA distress: path analysis. *Depression and Anxiety, 28*(3), 218-226. https://doi.org/10.1002/da.20774

Howorth, A. [Noggy Bloggy]. (2020, October 27). *What is depersonalization? (DP/DR)* [Video]. YouTube. https://www.youtube.com/watch?v=5_uAx6jUY74&t=10s

Hoyer, J., Braeuer, D., Crawcour, S., Klumbies, E., & Kirschbaum, C. (2013). Depersonalization/derealization during acute social stress in social phobia. *Journal of Anxiety Disorders, 27*(2), 178-187. https://doi.org/10.1016/j.janxdis.2013.01.002

Humpston, C., Harrow, M., & Rosen, C. (2020). Behind the opaque curtain: A 20-year longitudinal study of dissociative and first-rank symptoms in schizophrenia-spectrum psychoses, other psychoses and non-psychotic disorders. *Schizophrenia Research, 223*, 319-326. https://doi.org/10.1016/j.schres.2020.07.019

Hunter, E. C. M., Phillips, M. L., Chalder, T., Sierra, M., & David, A. S. (2003). Depersonalisation disorder: a cognitive-behavioural conceptualisation. *Behaviour Research and Therapy, 41*(12), 1451-1467. https://doi.org/10.1016/S0005-7967(03)00066-4

Hunter, E. C. M., Sierra, M., & David, A. S. (2004). The epidemiology of depersonalisation and derealisation. 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., Baker, D., Phillips, M. L., Sierra, M., & David, A. S. (2005). Cognitive-behaviour therapy for depersonalisation disorder: an open study. *Behaviour Research and Therapy, 43*(9), 1121-1130. https://doi.org/10.1016/j.brat.2004.08.003

Hunter, E. C. M., Charlton, J., & David, A. S. (2017). Depersonalisation and derealisation: assessment and management. *The BMJ, 356*, https://doi-org.uniessexlib.idm.oclc.org/10.1136/bmj.j745

Hunter, E. & David, A. (2021). Foreword by Dr Elaine Hunter and Professor Anthony David. In J. Perkins (Ed.), *Life on autopilot: A guide to living with depersonalization disorder* (pp. 12-15). Jessica Kingsley Publishers

Hunter, E. C. M., Wong, C. L. M., Gafoor, R., Lewis, G., & David, A. S. (2023). Cognitive behaviour therapy (CBT) for Depersonalization Derealization Disorder (DDD): a self-controlled cross-over study of waiting list vs. active treatment. *Cognitive Behaviour Therapy, 52*(6), 672-685. https://doi.org/10.1080/16506073.2023.2255744

International Society for Traumatic Stress Studies. (2024). *PTSD Checklist for DSM-5.* ISTSS. https://istss.org/clinical-resources/adult-trauma-assessments/ptsd-checklist-for-dsm-5/

Iverson, K. M., McLaughlin, K. A., Gerber, M. R., Dick, A., Smith, B. N., Bell, M. E., Cook, N., & Mitchell, K. S. (2013). Exposure to interpersonal violence and its associations with psychiatric morbidity in a U.S. national sample: A gender comparison. *Psychology of Violence, 3*(3), 273-287. https://doi.org/10.1037/a0030956

Jaspers, K. (1997). *General Psychopathology Volume Two.* The Johns Hopkins University Press.

Jay, E-L., Nestler, S., Sierra, M., McClelland, J., Kekic, M., & David, A. S. (2016). Ventrolateral prefrontal cortex repetitive transcranial magnetic stimulation in the treatment of depersonalization disorder: A consecutive case series. *Psychiatry Research, 240*, 118-122. https://doi.org/10.1016/j.psychres.2016.04.027

Jones, T. L., Baxter, M. A., & Khanduja, V. (2013). A quick guide to survey research. *Annals of The Royal College of Surgeons of England, 95* (1), 5-7. https://doi.org/10.1308/003588413X13511609956372

Jones, Z. (2018, February 27). Depersonalization in gender dysphoria: widespread and widely unrecognized. *Medium.* https://zinniajones.medium.com/depersonalization-in-gender-dysphoria-widespread-and-widely-unrecognized-baaac395bcb0

Judd, C. M., & Kenny, D. A. (1981). Process analysis: Estimating mediation in treatment evaluations. *Evaluation Review, 5*(5), 602-619. https://doi.org/10.1177/0193841X8100500502

Junglen, A., Hruska, B., Jensen, T., Boros, A., & Delahanty, D. L. (2019). Improving our understanding of the relationship between emotional abuse and substance use disorders: the mediating roles of negative urgency and posttraumatic stress disorder. *Substance Use & Misuse, 54*(9), 1569-1579. https://doi.org/10.1080/10826084.2019.1594905

Karr, T. M., Simonich, H., & Wonderlich, S. A. (2012). Psychological trauma and body image. In T. Cash (Ed.), *Encyclopedia of body image and human appearance* (pp. 700-706). Elsevier Inc. https://doi.org/10.1016/C2010-1-66177-9

Karris, B. C., Capobianco, X. W., Ross, L. (2017). Treatment of depersonalization disorder with repetitive transcranial magnetic stimulation. *Journal of Psychiatric Practice, 23*(2), 141-144. https://doi.org/10.1097/PRA.0000000000000215

Kasiulevičius, V., Sapoka, V., & Filipavičiūtė, R. (2006). Sample size calculation in epidemiological studies. *Gerontologija.* Retrieved June 09, 2025, from https://www.researchgate.net/publication/254847492_Sample_size_calculation_in_epidemiological_studies#fullTextFileContent

Katz, C., Tsur, N., Talmon, A., & Nicolet, R. (2021). Beyond fight, flight, and freeze: Towards a new conceptualization of peritraumatic responses to child sexual abuse based on retrospective accounts of adult survivors. *Child Abuse & Neglect, 112,* https://doi.org/10.1016/j.chiabu.2020.104905

Kemal, Ö. (2020). Power analysis and sample size, when and why?. *Turkish Archives of Otorhinolaryngology, 58*(1), 3-4

Kendall-Tackett, K. (2002). The health effects of childhood abuse: four pathways by which abuse can influence health. *Child Abuse & Neglect, 26*(6-7), 715-729. https://doi.org/10.1016/s0145-2134(02)00343-5

Kersting, A., Reutemann, M., Gast, U., Ohrmann, P., Suslow, T., Michael, N., & Arolt, V. (2003). Dissociative disorders and traumatic childhood experiences in transsexuals. *Journal of Nervous and Mental Disease, 191*(3), 182-189. https://doi.org/10.1097/01.NMD.0000054932.22929.5D

Kihlstrom, J. F. (2001). Dissociative Disorders. In H. E. Adams & P. B. Sutker (Eds.), *Comprehensive handbook of psychopathology* (pp.259-276). Springer.

King, C. D., Hill, S. B., Wolff, J. D., Bigony, C. E., Winternitz, S., Ressler, K. J., Kaufman, M. L., & Lebois, L. A. M. (2020). Childhood maltreatment type and severity predict depersonalization and derealization in treatment-seeking women with posttraumatic stress disorder. *Psychiatry Research, 292*, https://doi.org/10.1016/j.psychres.2020.113301

Kirby, A. (2024, April 15). Navigating the intersection of trauma and neurodiversity. *Do It.* https://doitprofiler.com/insight/navigating-the-intersection-of-trauma-and-neurodiversity/#:~:text=Developmental%20trauma%2C%20in%20particular%2C%20can,the%20presentation%20of%20neurodivergent%20traits.

Kontoangelos, K., Tsiori, S., Poulakou, G., Protopapas, K., Katsarolis, I., Sakka, V., Kavatha, D., Papadopoulos, A., Antoniadou, A., & Papageorgiou, C. C. (2016). Reliability validity, and psychometric properties of the Greek translation of the Cambridge Depersonalization Scale (CDS). *Materia Socio-Medica, 28*(5), 387-391. https://doi.org/10.5455/msm.2016.28.387-391

Kriukow, J. (2024, November 19). Understanding ontology, epistemology, positivism, and interpretivism: Foundations of research. *Linkedin.* https://www.linkedin.com/pulse/understanding-ontology-epistemology-positivism-research-kriukow-qcife/

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*(9), 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

Kroenke, K., Strine, T. W., Spitzer, R. L., Williams, J. B., Berry, J. T., & Mokdad, A. H. (2009). The PHQ-8 as a measure of current depression in the general population. *Journal of Affective Disorders, 114*(1-3), 163-173. https://doi.org/10.1016/j.jad.2008.06.026

Kroenke, K. (2021). PHQ-9: global uptake of a depression scale. *World Psychiatry, 20*(1), 135-136. https://doi.org/10.1002/wps.20821

Kurtulus, C., & Elemo, A. S. (2023). Childhood emotional neglect and risks of substance misuse: Meaning and purpose of life as a mediator. *International Journal of Mental Health, 22*(6), 3990-4003. https://doi.org/10.1007/s11469-023-01096-w

Lambert, M. V., Senior, C., Fewtrell, W. D., Phillips, M. L., & David, A. S. (2001). Primary and secondary depersonalisation disorder: A psychometric study. *Journal of Affective Disorders, 63*(1-3), 249-256. https://doi.org/10.1016/S0165-0327(00)00197-X

Lambert, M. V., Senior, C., Phillips, M. L., Sierra, M., Hunter, E., & David, A. S. (2001). Visual imagery and depersonalisation. *Psychopathology, 34*(5), 259-264. https://doi.org/10.1159/000049319

Lander, L., Howsare, J., & Byrne, M. (2013). The impact of substance use disorders on families and children: From theory to practice. *Social Work in Public Health, 28,* 194-205. https://doi.org/10.1080/19371918.2013.759005

Lanius, R. A., Vermetten, E., Loewenstein, R. J., Brand, B., Schmahl, C., Bremner, 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

Laoide, A. Ó., Egan, J., & Osborn, K. (2018). What was once essential, may become detrimental: The mediating role of depersonalization in the relationship between childhood emotional maltreatment and psychological distress in adults. *Journal of Trauma & Dissociation, 19*(5), 514-534. https://doi.org/10.1080/15299732.2017.1402398

Lashkay, A-M., Kinsella, E. L., & Muldoon, O. T. (2023). When trauma is stigmatized: Disidentification and dissociation in people affected by adverse childhood experiences. *Journal of Community & Applied Social Psychology, 33*(5), 1225-1240. https://doi.org/10.1002/casp.2702

Lassri, D., Bregman-Hai, N., Soffer-Dudek, N., & Shahar, G. (2022). The interplay between childhood sexual abuse, self-concept clarity, and dissociation: A resilience-based perspective. *Journal of Interpersonal Violence, 0*(0), 1-24. https://doi.org/10.1177/08862605221101182

Leaviss, J., & Uttley, L. (2014). Psychotherapeutic benefits of compassion-focused therapy: an early systematic review. *Psychological Medicine, 45*(5), 927-945. https://doi.org/10.1017/S0033291714002141

Lee, W. E., Kwok, C. H. T., Hunter, E. C. M., Richards, M., & David, A. S. (2012). Prevalence and childhood antecedents of depersonalisation syndrome in a UK birth cohort. *Social Psychiatry and Psychiatric Epidemiology, 47*(2), 253-261. https://doi.org/10.1007/s00127-010-0327-7

Lemche, E., Anilkumar, A., Giampietro, V. P., Brammer, M. J., Surguladze, S. A., Lawrence, N. S., Gasston, D., Chitnis, X., Williams, S. C. R., Sierra, M., Joraschky, P., & Phillips, M. L. (2008). Cerebral and autonomic responses to emotional facial expressions in depersonalisation disorder. *The British Journal of Psychiatry, 193*(3), 222-228. https://doi.org/10.1192/bjp.bp.107.044263

Leung, L. (2015). Validity, reliability and generalizability in qualitative research. *Journal of Family Medicine and Primary Care, 4*(3), 324-327. https://doi.org/10.4103/2249-4863.161306

Liebschutz, J. M., Buchanan-Howland, K., Chen, C. A., Frank, D. A., Richardson, M. A., Heeren, T. C., Cabral, H. J., & Rose-Jacobs, R. (2019). Childhood Trauma Questionnaire (CTQ) correlations with prospective violence assessment in a longitudinal cohort. *Psychological Assessment, 30*(6), 841-845. https://doi.org/10.1037/pas0000549

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Sage Publications.

Lobregt-van Buuren, E., Hoekert, M., & Sizoo, B. (2021). Autism, adverse events, and trauma. In A. M. Grabrucker (Ed.), *Autism Spectrum Disorders* (pp.33-42). Exon Publications. https://doi.org/10.36255/exonpublications.autismspectrumdisorders.2021.trauma

Loewenstein, R. J. (2018). Dissociation debates: everything you know is wrong. *Dialogues in Clinical Neuroscience, 20*(3), 229-242. https://doi.org/10.31887/DCNS.2018.20.3/rloewenstein

Lofthouse, K., Waite, P., & Černis, E. (2023). Developing an understanding of the relationship between anxiety and dissociation in adolescence. *Psychiatry Research, 324*, https://doi/org/10.1016/j.psychres.2023.115219

Lorenzini, E., Osorio-Galeano, S. P., Schmidt, C. R., & Cañon-Montañez, W. (2024). Practical guide to achieve rigor and data integration in mixed methods research. *Investigación y Educación en Enfermería, 42*(3), https://doi/org/10.17533/udea.iee.v42n3e02

Lundin, A. (2024). *Adulthood dissociation and its relationship to childhood maltreatment type* (Publication No. 30987822) [Doctoral dissertation, Alliant International University]. ProQuest.

Madden, S. P., & Einhorn, P. M. (2018). Cannabis-induced depersonalization-derealization disorder. *The American Journal of Psychiatry Residents' Journal, 13*(2), https://doi.org/10/1176/appi.ajp-rj.2018.130202

Magaldi, D., & Berler, M. (2020). Semi-structured interviews. In V. Zeigler-Hill & T. K. Shackelford (Eds.), *Encyclopedia of personality and individual differences* (pp. 4825-4830). Springer. https://doi.org/10.1007/978-3-319-24612-3_857

Mantovani, A., Simeon, D., Urban, N., Bulow, P., Allart, A., & Lisanby, S. (2011). Temporo-parietal junction stimulation in the treatment of depersonalization disorder. *Psychiatry Research, 186*(1), 138-140. https://doi.org/10.1016/j.psychres.2010.08.022

Maraldi, E. d. O. (2024). The link between dissociation and religious/spiritual experiences: A critical examination and comparison of existing hypotheses. In D. Yaden & M. v. Elk

(Eds.), *The Oxford handbook of psychedelic, religious, spiritual, and mystical experiences.* Oxford University Press. https://doi.org/10.1093/oxfordhb/9780192844064.013.31

Marples, A. (2023, July 03). What's the relationship between neurodiversity and trauma?. *Welldoing*. https://welldoing.org/article/whats-the-relationship-neurodiveristy-trauma

Marschall, A. (2024, February 13). *The four fear responses: Fight, flight, freeze, and fawn.* Verywell mind. https://www.verywellmind.com/the-four-fear-responses-fight-flight-freeze-and-fawn-5205083

Marshall, C., Semovski, V., & Stewart, S. L. (2020). Exposure to childhood interpersonal trauma and mental health service urgency. *Child Abuse & Neglect, 106*, https://doi.org/10.1016/j.chiabu.2020.104464

Marvin, K. (2011, January 11). *Patient Health Questionnaire (PHQ-9).* Stroke Engine. https://strokengine.ca/en/assessments/patient-health-questionnaire-phq-9/

Matthews, B., & Ross, L. (2010). *Research Methods: A practical guide for the social sciences*. Pearson Longman.

McDonald, N., Schoenebeck, S., & Forte, A. (2019). Reliability and inter-rater reliability in qualitative research: Norms and guidelines for CSCW and HCI practice. *Proceedings of the ACM on Human-Computer Interaction, 3*, 1-23. https://doi.org/10.1145/3359174

McGrath, C., Palmgren, P. J., & Liljedahl, M. (2018). Twelve tips for conducting qualitative research interviews. *Medical Teacher, 41*(9), 1002-1006. https://doi.org/10.1080/0142159X.2018.1497149

McKenzie, J. E., & Brennan, S. E. (2019). Chapter 12: Synthesizing and presenting findings using other methods. In J. P. T. Higgins, J. Thomas, J. Chandler, M. Cumpston, T. Li, M. J. Page & V. A. Welch (Eds.), *Cochrane handbook for systematic reviews of interventions* (2nd ed.). (pp. 321-348). Wiley-Blackwell.

McLaughlin, K. A., & Lambert, H. K. (2017). Child trauma exposure and psychopathology: Mechanisms of risk and resilience. *Current Opinion in Psychology, 14*, 29-34. https://doi.org/10.1016/j.copsyc.2016.10.004

Mcleod, S. (2023, October 13). P-value and statistical significance: What it is & why it matters. *Simply Psychology.* https://www.simplypsychology.org/p-value.html

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/10.1192/apt.11.2.92

Mercy, J. A., Hillis, S. D., Butchart, A., Bellis, M. A., Ward, C. L., Fang, X., & Rosenberg, M. L. (2017). Interpersonal violence: Global impact and paths to prevention. In C. N. Mock, R. Nugent, O. Kobusingye & K. R. Smith (Eds.) *Injury prevention and environmental health* (3rd ed.). (pp. 71-96). The International Bank for Reconstruction and Development. https://doi.org/10.1596/978-1-4648-0522-6_ch5

Michal, M., Lüchtenberg, M., Overbeck, G., & Fronius, M. (2006). Visual distortions and depersonalization-derealization syndrome. *Klinische Monatsblatter für Augenheilkunde, 223*(4), 279-284. https://doi.org/10.1055/s-2005-858716

Michal, M., Beutel, M. E., Jordan, J., Zimmermann, M., Wolters, S., & Heidenreich, T. (2007). Depersonalization, mindfulness, and childhood trauma. *Journal of Nervous and Mental Disease, 195*(8), 693-696. https://doi.org/10.1097/NMD.0b013e31811f4492

Michal, M., Glasemer, H., Zwerenz, R., Knebel, A., Wiltink, J., Brähler, E., & Beutel, M. E. (2011). Base rates for depersonalization according to the 2-item version of the Cambridge Depersonalization Scale (CDS-2) and its associations with depression/anxiety in the general population. *Journal of Affective Disorders, 128*(1-2), 106-111. https://doi/org/10.1016/j/jad.2010.06.033

Michal, M., Adler, J., Wiltink, J., Reiner, I., Tschan, R., Wölfling, K., Weimert, S., Tuin, I., Subic-Wrana, C., Beutel, M. E., & Zwerenz, R. (2016). A case series of 223 patients with depersonalization-derealization syndrome. *BMC Psychiatry, 16*, 1-11. https://doi.org/10.1186/s12888-016-0908-4

Migliavaca, C. B., Stein, C., Colpani, V., Barker, T. H. Munn, Z., & Falavigna, M. (2020). How are systematic reviews of prevalence conducted? A methodological study. *BMC Medical Research Methodology, 20* (1), https://doi.org/10.1186/s12874-020-00975-3

Millman, L. S. M., Huang, X., Wainipitapong, S., Medford, N., & Pick, S. (2024). Behavioural, autonomic, and neural responsivity in depersonalisation-derealisation disorder: A systematic review of experimental evidence. *Neuroscience & Biobehavioral Reviews, 163*, https://doi.org/10.1016/j.neublorev.2024.105783

Mind (2023, January). *Dissociation and dissociative disorders.* Mind. https://www.mind.org.uk/information-support/types-of-mental-health-problems/dissociation-and-dissociative-disorders/dissociative-disorders/#WhyMightItBeDifficultToGetDiagnosed

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), https://doi.org/10.7759/cureus.55419

Mittal, B. (2015). Self-concept clarity: Exploring its rols in consumer behaviour. *Journal of Economic Psychology, 46*, 98-110. https://doi.org/10.1016/j.joep.2014.11.003

Molina-Castillo, J. J., Martínez de la Iglesia, J., Colomer, C. A., Berrios, G., Sierra, M. J., & Luque R. (2006). Cross-cultural adaptation and validation of the Cambridge Depersonalisation Scale. *Actas Espanolas de Psiquiatria,* Retrieved February 23, 2025, from https://www.researchgate.net/publication/7047247_Cross-cultural_adaptation_and_validation_of_the_Cambridge_Depersonalisation_Scale

Moola, S., Munn, Z., Sears, K., Sfetcu, R., Currie, M., Lisy, K., Tufanaru, C., Qureshi, R., Mattis, P., & Mu, P. (2015). Conducting systematic reviews of association (etiology) The Joanna Briggs institute's approach. *International Journal of Evidence-Based Healthcare, 13* (3), 163-169. https://doi.org/10.1097/XEB.0000000000000064

Moon, K., & Blackman, D. (2017, May 02). A guide to ontology, epistemology, and philosophical perspectives for interdisciplinary researchers. *Integration and Implementation Insights.* https://i2insights.org/2017/05/02/philosophy-forinterdisciplinarity/#:~:text=Meanwhile%2C%20relativist%20ontology%20is%20based,any%20given%20time%20and%20place.

Moreno-Montero, E., Moreta-Herrera, R., Rodas, J. A., Oriol-Granado, X., Puerta-Cortés, D. X., Ferrufino-Borja, D., Diaz, R. G., Rivera, M. E. L., Samaniego-Pinho, A., Buenahora-Bernal, M., Rojas-Jara, C., & Vega-Arce, M. (2025). Cross-cultural measurement equivalence of the seven item general anxiety disorder scale (GAD-7) in college students of six countries of Latin American. *Journal of Affective Disorders, 380*, 598-606. https://doi.org/10.1016/j.jad.2025.03.188

Morstead, T., & Delongis, A. (2023). Searching for secrets, searching for self: Childhood adversity, self-concept clarity, and the motivation to uncover family secrets through direct-to-consumer genetic testing. *Journal of Genetic Counseling, 32*(3), 698-705. https://doi.org/10.1002/jgc4.1679

Mūller, F., Hansen, A., Kube, M., Arnetz, J. E., Alshaarawy, O., Achtyes, E. D., & Holman, H. T. (2024). Translation, cultural adaptation, and validation of the PHQ-9 and GAD-7 in Kinyarwanda for primary care in the United States. *PloS One, 19*(10), https://doi.org/10.1371/journal.pone.0302953

Munn, Z., Moola, S., Riitano, D., & Lisy, K. (2014). The development of a critical appraisal tool for use in systematic reviews addressing questions of prevalence. *International Journal of Health Policy and Management, 3* (3), 123-128. https://doi.org/10.15171/ijhpm.2014.71

Munn, Z., Barker, T. H., Moola, S., Tufanaru, C., Stern, C., McArthur, A., Stephenson, M., & Aromataris, E. (2020). Methodological quality of case series studies: an introduction to the JBI critical appraisal tool. *JBI Evidence Synthesis, 18*(10), 2127-2133. https://doi.org/10.11124/JBISRIR-D-19-00099

Murphy, R. J. (2023). Depersonalization/derealization disorder and neural correlates of trauma-related pathology: A critical review. *Innovations in Clinical Neuroscience, 20*(1-3), 53-59. https://www-ncbi-nlm-nih-gov.uniessexlib.idm.oclc.org/pmc/articles/PMC10132272/#B17

Mychailyszyn, M. P., Webermann, A., Brand, B. L., Sar, V., & Draijer, N. (2020). Differentiating dissociative from non-dissociative disorders: A meta-analysis of the structured clinical interview for DSM dissociative disorders (SCID-D). *Journal of Trauma & Dissociation, 22*(1), 19-34. https://doi.org/10.1080/15299732.2020.1760169

Myers, N. S., & Llera, S. J. (2020). The role of childhood maltreatment in the relationship between social anxiety and dissociation: A novel link. *Journal of Trauma & Dissociation, 21*(3), 319-336. https://doi.org/10.1080/15299732.2020.1719265

National Center for PTSD (2025a, March 25). *Dissociative subtype of PTSD.* U.S. Department of Veterans Affairs. Retrieved June 29, 2025, from https://www.ptsd.va.gov/professional/treat/essentials/dissociative_subtype.asp

National Center for PTSD (2025b, May 09). *PTSD Checklist for DSM-5 (PCL-5).* U.S. Department of Veterans Affairs. Retrieved June 29, 2025, from https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp#obtain

National Center for PTSD (2025c, March 25). *Life Events Checklist for DSM-5 (LEC-5).* U.S. Department of Veterans Affairs. Retrieved June 29, 2025, from https://www.ptsd.va.gov/professional/assessment/te-measures/life_events_checklist.asp#:~:text=There%20is%20no%20formal%20scoring,Not%20sure;%20Doesn't%20apply

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

National Health Service, (2022, May 13). *Overview – Post-traumatic stress disorder.* NHS. https://www.nhs.uk/mental-health/conditions/post-traumatic-stress-disorder-ptsd/overview/

National Institute for Health and Care Excellence. (n.d.). *How we develop NICE guidelines.* NICE. Retrieved June 26, 2025, from https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/how-we-develop-nice-guidelines

National Institute for Health and Care Excellence. (2003). *National Institute for Health and Care Excellence: Guidelines.* NICE. https://www-ncbi-nlm-nih-gov.uniessexlib.idm.oclc.org/books/NBK11822/#:~:text=They%20are%20based%20on%20the,of%20people%20by%20health%20professionals

National Institute for Health and Care Excellence. (2024, September). *How should I assess a person with suspected functional neurological disorder?.* NICE. https://cks.nice.org.uk/topics/functional-neurological-disorder/diagnosis/assessment/

National Institute for Health and Care Excellence. (2025, February). *When should I suspect post-traumatic stress disorder (PTSD)?.* NICE. https://cks.nice.org.uk/topics/post-traumatic-stress-disorder/diagnosis/diagnosis/#:~:text=PTSD%20with%20delayed%20expression%20is,things%20are%20not%20real%22).

NovoPsych. (2025). *Life Events Checklist for DSM-5 (LEC-5).* NovoPsych. https://novopsych.com/assessments/diagnosis/life-events-checklist-5-lec-5/#:~:text=The%20scale%20displayed%20good%20test,et%20al.%2C%202020).

O'Connor, C. & Joffe, H. (2020). Intercoder reliability in qualitative research: Debates and practical guidelines. *International Journal of Qualitative Methods, 19*, https://doi.org/10.1177/1609406919899220

Office for Health Improvement & Disparities. (2022, November 02). *Working definition of trauma-informed practice.* Gov UK. https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice

O'Neill, T., Maguire, A., & Shevlin, M. (2021). Sexual trauma in childhood and adulthood as predictors of psychotic-like experiences: The mediating role of dissociation. *Child Abuse Review, 30*(5), 431-443. https://doi.org/10.1002/car.2705

Orrù, G., Bertelloni, D., Cesari, V., Conversani, C., & Gemignani, A. (2021). Targeting temporal parietal junction for assessing and treating disembodiment phenomena: a systematic review of TMS effect on depersonalization and derealization disorders

(DPD) and body illusions. *AIMS Neuroscience, 8*(2), 181-194. https://doi.org/10.3934/Neuroscience.2021009

Ouzzani, M., Hammady, H., Federowicz, Z., & Elmagarmid, A. (2016). Rayyan – a web and mobile app for systematic reviews. *Systematic Reviews, 5*, 1-10. https://doi.org/10.1186/s13643-016-0384-4

Paetzold, R. L., & Rholes, W. S. (2021). The link from child abuse to dissociation: The roles of adult disorganized attachment, self-concept clarity, and reflective functioning. *Journal of Trauma & Dissociation, 22*(5), 615-635. https://doi.org/10.1080/15299732.2020.1869654

Paivio, S. C., & Cramer, K. M. (2004). Factor structure and reliability of the Childhood Trauma Questionnaire in a Canadian undergraduate student sample. *Child Abuse & Neglect, 28*(8), 889-904. https://doi.org/10.1016/j.chiabu.2004.01.011

Paterra, A. (2024, August 31). The advantage and disadvantages of using mixed methods for survey work. *Linkedin.* https://www.linkedin.com/pulse/advantages-disadvantages-using-mixed-methods-survey-paterra-ph-d--ci83c/

Perkins, J. (2021, July 13a). ‘Nothing feels real’: My life with depersonalisation disorder. *The Bristol Cable.* https://thebristolcable.org/2021/07/nothing-feels-real-my-life-with-depersonalisation-disorder/

Perkins, J. (2021b). *Life on Autopilot: A guide to living with depersonalization disorder.* Jessica Kingsley Publishers.

Phillips, M. L., & Sierra, M. (2003). Depersonalization disorder: a functional neuroanatomical perspective. *Stress, 6*(3), 157-165. https://doi.org/10.1080/1025389031000138538

Pillay, A. S. (2024). Research instruments and interpretivism: Evidence of constructivism and co-constructivism. *Future Journal.* Retrieved July 21, 2025, from https://www.futurexjournal.net/wp-content/uploads/2024/07/Allen-Pillay.pdf

Polanin, J. R., Pigott, T. D., Espelage, D. L. & Grotpeter, J. K. (2019). Best practice guidelines for abstract screening large-evidence systematic reviews and meta-analyses. *Research Synthesis Methods, 10*(3), 330-342. https://doi.org/10.1002/jrsm.1354

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC methods programme.* Lancaster University. https://doi.org/10.13140/2.1.1018.4643

Prince, M. (2011). Epidemiology. In P. Wright, J. Stern & M. Phelan (Eds.), *Core Psychiatry* (pp.115-129). Saunders Ltd. https://doi.org/10.1016/B978-0-7020-3397-1.00009-4

Puljak, L. (2017). If there is only one author or only one database was searched, a study should not be called a systematic review. *Journal of Clinical Epidemiology, 91,* 4-5. https://doi.org/10.1016/j.jclinepi.2017.08.002

Quiñones, M. A. (2022). Adverse childhood experiences and dissociative disorders: A causal pathway based on the disruptive impacts of cumulative childhood adversity and distress-related dissociation. In M. J. Dorahy, S. N. Gold & J. A. O'Neil (Eds.), *Dissociation and the dissociative disorders: Past, Present, Future* (pp.209-222). Routledge.

Rafi, A. T., & Prabalkumari, S. S. (2022). Cognitive Analytic Therapy: An innovative psychotherapy framework in the Indian context. *Indian Journal of Psychological Medicine, 45*(6), 634-639. https://doi.org/10.1177/02537176221081778

Rajkumar, R. P. (2022). The molecular genetics of dissociative symptomatology: A transdiagnostic literature review. *Genes, 13*(5), https://doi.org/10.3390/genes13050843

Reed, G. M., First, M. B., Kogan, C. S., Hyman, S. E., Gureje, O., Gaebel, W., Maj., M., Stein, D. J., Maercker, A., Tyrer, P., Claudino, A., Garralda, E., Salvador-Carulla, L., Ray, R., Saunders, J. B., Dua, T., Poznyak, V. Medina-Mora, M. E., Pike, K. M., … Saxena, S. (2019). Innovations and changes in the ICD-11 classification of mental, behavioural and neurodevelopmental disorders. *World Psychiatry, 18*(1), 3-19. https://doi.org/10.1002/wps.20611

Reinert, K. G., Campbell, J. C., Bandeen-Roche, K., Lee, J. W., & Szanton, S. (2015). The role of religious involvement in the relationship between early trauma and health outcomes among adult survivors. *Journal of Child & Adolescent Trauma, 9*(3), 231-241. https://doi.org/10.1007/s40653-015-0067-7

Rethink Mental Illness. (n.d.). *Dissociation and dissociative identity disorder (DID).* Rethink Mental Illness. Retrieved June 26, 2025, from https://www.rethink.org/advice-and-information/about-mental-illness/mental-health-conditions/dissociation-and-dissociative-identity-disorder-did/#:~:text=What%20treatment%20should%20I%20be,mental%20health'%20by%20clicking%20here.

Rethink Mental Illness. (2022, June 27). Living with DPDR – “My face in the mirror was unrecognisable”. *Rethink Mental Illness.* https://www.rethink.org/news-and-stories/blogs/2022/06/living-with-dpdr-my-face-in-the-mirror-was-unrecognisable/

Rigby, P. (2024, April 05). How medical negligence can effect your mental health. *Patient Claim Line.* https://www.patientclaimline.com/expert-information/how-accurate-is-your-mental-health-diagnosis/#:~:text=When%20misdiagnosis%20occurs%2C%20the%20symptoms%20of%20the%20mental%20illness%20that,or%20more%20severe%20depressive%20episodes.&text=Many%20people%20suffering%20from%20mental,the%20correct%20diagnosis%20and%20treatment.

Roelofs, K. (2017). Freeze for action: neurobiological mechanisms in animal and human freezing. *Philosophical Transactions of the Royal Society B Biological Sciences, 372*(1718), https://doi.org/10.1098/rstb.2016.0206

Rosagro-Escámez, F., Gutiérrez-Fernández, N., Gómez-Meriono, P., de la Vega, I., & Carrasco, J. L. (2011). The efficacy of lamotrigine in a resistant case of depersonalization disorder. *Actas Españolas de Psiquiatria.* Retrieved June 20, 2025, from https://actaspsiquiatria.es/index.php/actas/article/view/694/1066

Ruslin, R., Mashuri, S., Rasak, M. S. A., Alhabsyi, F., Syam, H. (2022). Semi-structured interview: A methodological reflection on the development of a qualitative research instrument in educational studies. *Journal of Research & Method in Education, 12*(1), 22-29. https://doi.org/10.9790/7388-1201052229

Ryle, A. (2005). Cognitive Analytic Therapy. In J. C. Norcross & M. R. Goldfried (Eds.), *Handbook of psychotherapy integration* (2nd ed.). (pp.196-217). Oxford University Press.

Saini, F., Ponzo, S., Silvestrin, F., Fotopoulou, A., & David, A. S. (2022). Depersonalization disorder as a systematic downregulation of interoceptive signals. *Scientific Reports, 12*(1), https://doi.org/10.1038/s41598-022-22277-y

Sar, V., Alioğlu, F., & Akyuz, G. (2017). Depersonalization and derealization in self-report and clinical interview: The spectrum of borderline personality disorder, dissociative disorders, and healthy controls. *Journal of Trauma & Dissociation, 18*(4), 490-506. https://doi.org/10.1080/15299732.2016.1240737

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2017). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality and Quantity, 52*(4), 1893-1907. https://doi.org/10.1007/s11135-017-0574-8

Schäfer, J. (2025). Depersonalization/derealization disorder: A comprehensive theoretical formulation. *European Journal of Trauma & Dissociation, 9*(4), https://doi.org/10.1016/j.ejtd.2025.100597

Schimmenti, A., Billieux, J., Santoro, G., Casale, S., & Starcevic, V. (2022). A trauma model of substance use: Elaboration and preliminary validation. *Addictive Behaviors, 134,* https://doi.org/10.1016/j.addbeh.2022.107431

Schlax, J., Wiltink, J., Beutel, M. E., Münzel, T., Pfeiffer, N., Wild, P., Blettner, M., Kerahrodi, J. G., & Michal, M. (2020). Symptoms of depersonalization/derealization are independent risk factors for the development or persistence of psychological distress in the general population: Results from the Gutenberg health study. *Journal of Affective Disorders, 273*, 41-47. https://doi.org/10.1016/j.jad.2020.04.018

Schlozman, S. C., & Nonacs, R. M. (2008). Chapter 35 – Dissociative disorders. In T. A. Stern, J. F. Rosenbaum, M. Fava, J. Biederman & S. L. Rauch (Eds.), *Massachusetts general hospital comprehensive clinical psychiatry* (pp. 481-486). Mosby. https://doi.org/10.1016/B978-0-323-04743-2.50037-8

Schmidt, M. R., Narayan, A. J., Atzi, V. M., Rivera, L. M., & Lieberman, A. F. (2020). Childhood maltreatment on the Adverse Childhood Experiences (ACEs) scale versus the Childhood Trauma Questionnaire (CTQ) in a perinatal sample. *Journal of Aggression, Maltreatment & Trauma, 29*(1), 38-56. https://doi.org/10.1080/10926771.2018.1524806

Schumaker, J. F. (1995). *The corruption of reality: A unified theory of religion, hypnosis, and psychopathology.* Prometheus.

Sedeño, L., Couto, B., Melloni, M., Canales-Johnson, A., Yoris, A., Baez, S., Esteves, S., Velásquez, M., Barttfeld, P., Sigman, M., Kichic, R., Chialvo, D., Manes, F., Bekinschtein, T. A., & Ibanez, A. (2014). How do you feel when you can't feel your body? Interoception, functional connectivity and emotional processing in Depersonalization-Derealization Disorder. *PLOS One, 9*(6), https://doi.org/10.1371/journal.pone.0098769

Seedat, S., Scott, K. M., Angermeyer, M. C., Berglund, P., Bromet, E. J., Brugha, T. S., Demyttenaere, K., de Girolamo, G, Haro, J. M., Jin, R., Karam, E. G., Kovess-Masfety, V., Levinson, D., Mora, M. E. M., Ono, Y., Ormel, J., Pennell, B., Posada-Villa, J., Sampson, N. A., … Kessler, R. C. (2009). Cross-national associations between gender and mental disorders in the WHO world mental health surveys. *Archives of General Psychiatry, 66*(7), 785-795. https://doi.org/10.1001/archgenpsychiatry.2009.36

Senior, C., Hunter, E., Lambert, M. V., Medford, N. C., Sierra, M., Phillips, M. L., & David, A. S. (2001). Depersonalisation. *The Psychologist, 14*(3), 128-132. https://cms.bps.org.uk/sites/default/files/2022-11/depers.pdf

Shim, S., Kim, D., & Kim, E. (2024). Dissociation as a mediator of interpersonal trauma and depression: adulthood versus childhood interpersonal traumas. *BMC Psychiatry, 24*, https://doi.org/10.1186/s12888-024-06095-2

Shin, C., Lee, S-H, Han, K-M., Yoong, H-K., & Han, C. (2019). Comparison of the usefulness of the PHQ-8 and PHQ-9 for screening for major depressive disorder: Analysis of psychiatric outpatient data. *Psychiatry Investigation, 16*(4), 300-305. https://doi.org/10.30773/pi.2019.02.01

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. (1998). Depersonalization: neurobiological perspectives. *Biological Psychiatry, 44*(1), 898-908. https://doi.org/10.1016/S0006-3223(98)00015-8

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

Sierra, M., Baker, D., Medford, N., Lawrence, E., Patel, M., Phillips, M. L., & David, A. S. (2006). Lamotrigine as an add-on treatment for depersonalization disorder: a retrospective study of 32 cases. *Clinical Neuropharmacology, 29*(5), 253-258. https://doi.org/10.1097/01.WNF.0000228368.17970.DA

Sierra-Siegert, M., & David, A. S. (2007). Depersonalization and individualism: The effect of culture on symptom profiles in panic disorder. *The Journal of Nervous and Mental Disease, 195*(12), 989-995. https://doi.org/10.1097/NMD.0b013e31815c19f7

Sim, M., Kim, S-Y., & Suh, Y. (2022). Sample size requirements for simple and complex mediation models. *Educational and Psychological Measurement, 82*(1), 76-106. https://doi.org/10.1177/00131644211003261

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

Simeon, D., Guralnik, O., Schmeidler, J., Sirof, B., & Knutelska, M., (2001). The role of childhood interpersonal trauma in depersonalization disorder. *The American Journal of Psychiatry, 158*(7), 1027-1033. https://doi.org/10.1176/appi.ajp.158.7.1027

Simeon, D., Knutelska, M., Nelson, D., & Guralnik, O. (2003). Feeling unreal: a depersonalization disorder update of 117 cases. *The Journal of Clinical Psychiatry, 64*(9), 990-997. https://doi.org/10.4088/jcp.v64n0903

Simeon, D., & Abugel, J. (2006). *Feeling Unreal: Depersonalization disorder and the loss of the self.* Oxford University Press.

Simeon, D., Smith, R. J., Knutelska, M., & Smith, L. M. (2008). Somatoform dissociation in depersonalization disorder. *Journal of Trauma & Dissociation, 9*(3), 335-348. https://doi.org/10.1080/15299730802139170

Simeon, D., Giesbrecht, T., Knutelska, M., Smith, R. J., & Smith, L. M., (2009). Alexithymia, absorption, and cognitive failures in depersonalization disorder: a comparison to posttraumatic stress disorder and healthy volunteers. *Journal of Nervous and Mental Disease, 197*(7), 492-498. https://doi.org/10.1097/NMD.0b013e3181aaef6b

Simeon, D., Kozin, D. S., Segal, K., & Lerch, B. (2009). Is depersonalization disorder initiated by illicit drug use any different? A survey of 384 adults. *The Journal of Clinical Psychiatry, 70*(10), 1358-1364. https://doi.org/10.4088/JCP.08m04370

Simeon, D., & Knutelska, M. (2022). The role of fearful attachment in depersonalization disorder. *European Journal of Trauma & Dissociation, 6*(3), https://doi.org/10.1016/j.ejtd.2022.100266

Simeon, D., & Stein, D. J. (2024). *Depersonalization/derealization and its relationship to mood and anxiety disorders in the National Comorbidity Survey-Replication (NCS-R)*. Research Square. https://doi.org/10.21203/rs.3.rs-4874891/v1

Smart TMS. (2016, August 23). Does the NHS cover rTMS in England?. *Smart TMS.* https://www.smarttms.co.uk/news/nhs-cover-rtms-england#:~:text=Repetitive%20Transcranial%20Magnetic%20Stimulation,the%20short%20to%20mid%20term.

Smith, C. (2020). *What is a person?: Rethinking humanity, social life, and the moral good from the person up.* The University of Chicago Press.

Soffer-Dudek, N. (2023). Obsessive-compulsive symptoms and dissociative experiences: Suggested underlying mechanisms and implications for science and practice. *Frontiers in Psychology, 14,* https://doi.org/10.3389/fpsyg.2023.1132800

Sol, K., & Heng, K. (2022). Understanding epistemology and its key approaches in research. *Cambodian Journal of Educational Research, 2*(2), 80-89. https://doi.org/10.62037/cjer.2022.02.02.05

Somer, E., Amos-Williams, T., & Stein D. J. (2013). Evidence-based treatment for depersonalisation-derealisation disorder (DPRD). *BMC Psychology, 1*(1), https://doi.org/10.1186/2050-7283-1-20

Song, M., Zheng, S., Song, N., Zhu, H., Jia, Y., Dai, Z., Liu, X., Wu, Z., Duan, Y., Huang, Z., Chen, J., & Jia, H. (2024). Clinical Characteristics of 217 Chinese cases with depersonalization/derealization disorder. *BMC Psychiatry, 24*(1), https://doi.org/10.1186/s12888-024-06028-z

Spiegel, D., & Cardeña, E. (1991). Disintegrated experience: The dissociative disorders revisited. *Journal of Abnormal Psychology, 100*(3), 366-378. https://doi.org/10.1037//0021-843x.100.3.366

Spiegel, D. (2023, May 03). Depersonalization/derealization disorder. *MSD Manual.* Retrieved May 30, 2025, from https://www.msdmanuals.com/professional/psychiatric-disorders/dissociative-disorders/depersonalization-derealization-disorder?ruleredirectid=742

Spiegel, D. (2025, June 03). Dissociative subtype of posttraumatic stress disorder. *MSD Manual.* Retrieved July 11, 2025, from https://www.msdmanuals.com/professional/psychiatric-disorders/dissociative-disorders/dissociative-subtype-of-posttraumatic-stress-disorder

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: The GAD-7. *Archives of Internal Medicine, 166*(10), 1092-1097. https://doi.org/10.1001/archinte.166.10.1092

Steinberg, M., Cicchetti, D., Buchanan, J., & Hall, P. (1993). Clinical assessment of dissociative symptoms and disorders: The Structured Clinical Interview for DSM-IV Dissociative Disorders (SCID-D). *Dissociation: Progress in the Dissociative Disorders.* Retrieved May 30, 2025, from https://psycnet-apa-org.uniessexlib.idm.oclc.org/record/1994-29796-001

Stevenson, A., Beltran, M., Misra, S., Ametaj, A. A., Bronkhorst, A., Gelaye, B., Koenen, K. C., Pretorius, A., Stein, D. J., & Zingela, Z. (2023). Trauma exposure and psychometric properties of the life events checklist among adults in South Africa. *European Journal of Pscyhotraumatology, 14*(1), https://doi.org/10.1080/20008066.2023.2172257

Sugiura, M., Hirosawa, M., Tanaka, S., Nishi, Y., Yamada, Y., & Mizuno, M. (2009). Reliability and validity of a Japanese version of the Cambridge depersonalization scale as a screening instrument for depersonalization disorder. *Psychiatry and Clinical Neurosciences, 63*(3), 314-321. https://doi.org/10.1111/j.1440-1819.2009.01939.x

Sürig, L., Kerbage, H., Courtabessis, E., Diaz, E., Visier, A., Fongaro, E., & Purper-Ouakil, D. (2024). Attention deficit hyperactivity disorder, self-esteem and the impact of treatments. *L'Encéphale, 50*(6), 603-609. https://doi.org/10.1016/j.encep.2023.11.009

Suszek, H., Fronczyk. K., Kopera, M., Maliszewski, N., Łyś, E. A. (2018). Psychometric properties of the Polish version of the Self-Concept Clarity Scale (SCCS). *Current Issues in Personality Psychology, 6*(3), 181-187. https://doi.org/10.5114/CIPP.2018.75842

Swaim, E. (2022, November 07). Dissociation as a defense mechanism: Why it happens and how to handle it. *Healthline.* https://www.healthline.com/health/mental-health/dissociative-defense-mechanism

Swains, H. (2015, September 04). Depersonalisation disorder: the condition you've never heard of that affects millions. *The Guardian.* https://www.theguardian.com/society/2015/sep/04/depersonalisation-disorder-the-condition-youve-never-heard-of-that-affects-millions

Sweeney, A., Filson, B., Kennedy, A., Collinson, L., & Gillard, S. (2018). A paradigm shift: relationships in trauma-informed mental health services. *BJPsych Advances, 24*(5), 319-333. https://doi.org/10.1192/bja.2018.29

Tariq, S., & Woodman, J. (2013). Using mixed methods in health research. *Journal of the Royal Society of Medicine Short Reports, 4*(6), https://doi.org/10.1177/2042533313479197

Tees, Esk and Wear Valleys NHS Foundation Trust. (2020, December 16). *Cognitive analytic therapy (CAT).* NHS. https://www.tewv.nhs.uk/about-your-care/treatments-therapies/cognitive-analytic-therapy/

Teymoori, A., Gorbunova, A., Haghish, F. E., Real, R., Zeldovich, M., Wu, Y-J., Polinder, S., Asendorf, T., Menon, D., Center-Tbi Investigators and Participants & Steinbüchel, N. V. (2020). Factorial structure and validity of depression (PHQ-9) and anxiety (GAD-7) scales after traumatic brain injury. *Journal of Clinical Medicine, 9*(3), 873. https://doi.org/10.3390/jcm9030873

Thal, S. B., Daniels, J. K., & Jungaberle, H. (2019). The link between childhood trauma and dissociation in frequent users of classic psychedelics and dissociatives. *Journal of Substance Use, 24*(5), 524-531. https://doi.org/10.1080/14659891.2019.1614234

The Human Condition Editorial Team. (2022, September 11). *The Childhood Trauma Questionnaire.* The Human Condition. https://thehumancondition.com/childhood-trauma-questionnaire-ctq/

Theocharous, G. (2024, August 1). Virtual vs in-person interviews: weighing the pros and cons. *Citation Group.* https://citationgroup.co.nz/resources/virtual-vs-in-person-interviews-weighing-the-pros-and-cons/#:~:text=Convenience:%20virtual%20interviews%20offer%20unmatched,leads%20to%20more%20genuine%20conversations.

Thomson, P., & Jaque, V. (2018). Depersonalization, adversity, emotionality, and coping with stressful situations. *Journal of Trauma & Dissociation, 19*(2), 143-161. https://doi.org/10.1080/15299732.2017.1329770.

Tod, D., Booth, A., & Smith, B. (2022). Critical appraisal. *International Review of Sport and Exercise Psychology, 15*(1), 52-72. https://doi.org/10.1080/1750984X.2021.1952471

Tomalski, R., & Pietkiewicz. (2022). Depersonalisation – a key to understand the complexity of dissociative phenomena. *Journal of Psychiatry and Clinical Psychology, 22*(3), 166-174. https://doi.org/10.15557/PiPK.2022.0022

Tracy, N. (2022, January 12). *The amazing history of Dissociative Identity Disorder (DID).* HealthyPlace. Retrieved December 20, 2022, from https://www.healthyplace.com/abuse/dissociative-identity-disorder/the-amazing-history-of-dissociative-identity-disorder-did

Tripathy, J. P. (2013). Secondary data analysis: Ethical issues and challenges. *Iranian Journal of Public Health.* Retrieved January 29, 2023, from https://www-ncbi-nlm-nih-gov.uniessexlib.idm.oclc.org/pmc/articles/PMC4441947/

Trujillo, M., Brown, A., Watson, D., Croft-Caderao, K., & Chimielewski, M. (2024). The Dissociative Experiences Scale: An empirical evaluation of long-standing concerns. *Psychology of Consciousness: Theory, Research, and Practice, 11*(4), 477-492. https://doi.org/10.1037/cns0000334

Turner, D. (2020, March 12). Should you use inter-rater reliability in qualitative coding?. *Quirkos*. https://www.quirkos.com/blog/post/inter-rater-reliaiblity-qualitative-coding-data/

University Libraries. (2022, May 02). *Systematic Reviews: Step 6: Assess quality of included studies.* UNC. https://guides.lib.unc.edu/systematic-reviews/assess-quality#:~:text=You%20should%20choose%20a%20Quality,tools%20for%20many%20study%20designs.

Uptas, A. (2019, March 13). Artist creates comic illustrating what it's like to live with a depersonalization disorder for the last 3 years. *deMilked.* https://www.demilked.com/life-with-depersonalization-derealisation-disorder-planetmclulu/

Van der Braak, K., Ghannad, M., Orelio, C., Heus, P., Damen, J. A. A., Spijker, R., Robinson, K., Lund, H., & Hooft, L. (2022). The score after 10 years of registration of systematic review protocols. *Systematic Reviews, 11*(1), https://doi.org/10.1186/s13643-022-02053-9

Van der Cruijsen, R., & Boyer, B. E. (2021). Explicit and implicit self-esteem in youth with autism spectrum disorders. *Autism, 25*(2), 349-360. https://doi.org/10.1177/1362361320961006

Van Ijzendoorn, M. H., & Schuengel, C. (1996). The measurement of dissociation in normal and clinical populations: Meta-analytic validation of the Dissociative Experiences Scale (DES). *Clinical Psychology Review, 16*(5), 365-382. https://doi.org/10.1016/0272-7358(96)00006-2

Vasileiou, K., Barnett, J., Thorpe, S., & Young T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology, 18*(1), https://doi.org/10.1186/s12874-018- 0594-7

Vertommen, T., Kampen, J., Veldhoven, N. S., Uzieblo, K., & Eede, F. V. D. (2018). Severe interpersonal violence against children in sport: Associated mental health problems and quality of life in adulthood. *Child Abuse & Neglect, 76*, 459-468. https://doi.org/10.1016/j.chiabu.2017.12.013

Vonderlin, R., Kleindienst, N., Alpers, G. W., Bohus, M., Lyssenko, L., & Schmahl, C. (2018). Dissociation in victims of childhood abuse or neglect: a meta-analytic review. *Psychological Medicine, 48*(15), 2467-2476. https://doi.org/10.1017/S003329178000740

Walby, S., & Allen, J. (2004). *Domestic violence, sexual assault and stalking: findings from the British crime survey.* City Research Online. https://openaccess.city.ac.uk/id/eprint/21697/1/Domesticviolencefindings_2004_5BritishCrimeSurvey276.pdf

Walling, D. P., Goodwin, J. M., & Cole, C. M. (1998). Dissociation in a transsexual population. *Journal of sex education and therapy, 23*(2), 121-123. https://doi.org/10.1080/01614576.1998.11074218

Wang, S., Zheng, S., Zhang, 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

Wasti, S. P., Simkhada, P., van Teijlingen, E. R., Sathian, B., & Banerjee, I. (2022). The growing importance of mixed-methods research in health. *Nepal Journal of Epidemiology, 12*(1), 1175-1178. https://doi.org/10.3126/nje.v.12i1.43633

Weathers, F. W., Litz, B. T., Keane, T. M., Palmieri, P. A., Marx, B. P., and Schnurr, P.P. (2013). *The PTSD Checklist for DSM-5 (PCL-5).* https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp#obtain

Webster, E. M. (2022). The impact of adverse childhood experiences on health and development in young children. *Global Pediatric Health, 9,* https://doi.org/10.1177/2333794X221078708

Weir, R. (2024). Differentiating risk: The association between relationship type and risk of repeat victimization of domestic abuse. *Policing: A Journal of Policy and Practice, 18*, https://doi.org/10.1093/police/paae024

Wu, J., Watkins, D., Hattie, J. (2010). Self-concept clarity: A longitudinal study of Hong Kong adolescents. *Personality and Individual Differences, 48*(3), 277-282. https://doi.org/10.1016/j.paid.2009.10.011

Meteyard, L. (2022, March 16). *Learn about depersonalization and derealization.* Psychology Tools. https://www.psychologytools.com/articles/learn-about-depersonalization-and-derealization

Whiting, L. S. (2008). Semi-structured interviews: guidance for novice researchers. *Nursing Standard, 22*(23), 35-40. https://doi.org/10.7748/ns2008.02.22.23.35.c6420

Wilkhoo, H. S., Islam, A. W., Reji, F., Sanghvi, L., Potdar, R., & Solanki, S. (2024). Depersonalization-derealization disorder: Etiological mechanism, diagnosis and management. *Discoveries, 12*(2), https://doi.org/10.15190/d.2024.09

Wolf, E. J., Mitchell, K. S., Sadeh, N., Hein, C., Fuhrman, I., Pietrzak, R. H., & Miller, M. W. (2017). The dissociative subtype of PTSD scale: Initial evaluation in a national sample of trauma-exposed veterans. *Assessment, 24*(4), 503-516. https://doi.org/10.1177/1073191115615212

Wong, A., Dirghangi, S. R., & Hart, S. R. (2019). Self-concept clarity mediates the effects of adverse childhood experiences on adult suicide behavior, depression, loneliness, perceived stress, and life distress. *Self and Identity, 18*(3), 1-20. https://doi.org/10.1080/15298868.2018.1430906

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines.* World Health Organization.

World Health Organization. (2022). *International statistical classification of diseases and related health problems* (11th ed.). https://icd.who.int/en

Yang, J., Millman, L. S. M., David, A. S., & Hunter, E. C. M. (2023). The Prevalence of Depersonalization-Derealization Disorder: A Systematic Review. *Journal of Trauma & Dissociation, 14,* 1-34. https://doi.org/10.1080/15299732.2022.2079796

Yoon, A. S., Jik, H., Lee, D., & Moon, I. (2023). Social determinants of mental health. In H. S. Friedman & C. H. Markey (Eds.). *Encyclopedia of Mental Health* (3rd ed.). (pp.274-285). Elsevier Inc.

Young people, (n.d.). University of Bristol. Retrieved February 02, 2023, from http://www.bristol.ac.uk/alspac/participants/our-participants/young-people/

Zamawe, F. C. (2015). The implication of using NVivo software in qualitative Data Analysis: Evidence-based reflections. *Malawi Medical Journal, 27*(1), 13-15. https://doi.org/10.4314/mmj.v27i1.4

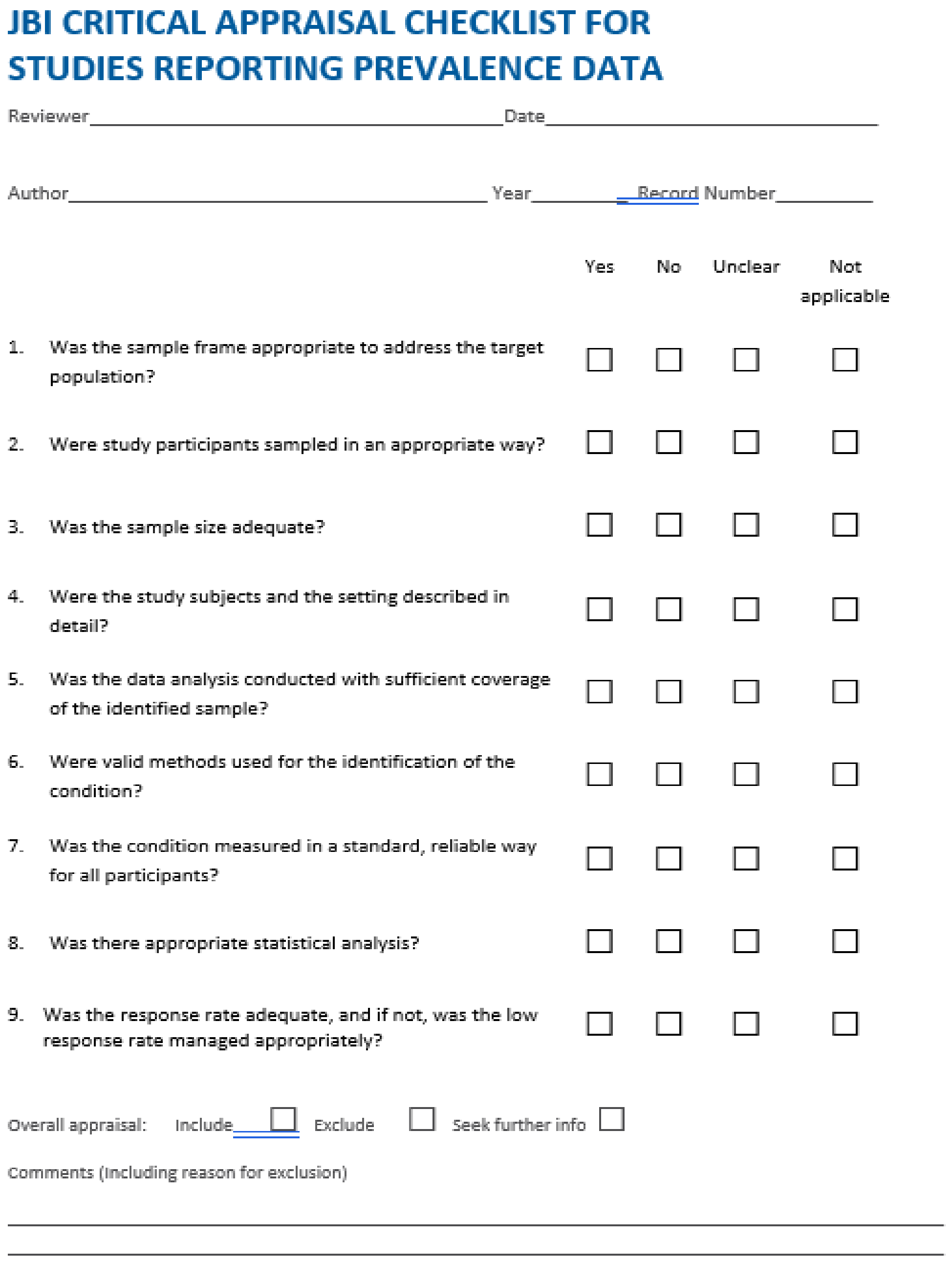
Zhang, H., Wang, W., & Wei, Q. (2023). A meta-analytic review of the impact of child maltreatment on self-esteem: 1981 to 2021. *Trauma, Violence, & Abuse, 24*(5), 3398-3411. https://doi.org/10.1177/15248380221129587

Appendix A

Quality Assessment Tool

Below are copies of the quality assessment tools used to assess the quality of the papers identified.

Figure A1



JBI CRITICAL APPRAISAL CHECKLIST FOR STUDIES REPORTING PREVALENCE DATA

Reviewer______________________________ Date______________________

Author______________________________ Year________ Record Number__________

	Yes	No	Unclear	Not applicable
1. Was the sample frame appropriate to address the target population?	☐	☐	☐	☐
2. Were study participants sampled in an appropriate way?	☐	☐	☐	☐
3. Was the sample size adequate?	☐	☐	☐	☐
4. Were the study subjects and the setting described in detail?	☐	☐	☐	☐
5. Was the data analysis conducted with sufficient coverage of the identified sample?	☐	☐	☐	☐
6. Were valid methods used for the identification of the condition?	☐	☐	☐	☐
7. Was the condition measured in a standard, reliable way for all participants?	☐	☐	☐	☐
8. Was there appropriate statistical analysis?	☐	☐	☐	☐
9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	☐	☐	☐	☐

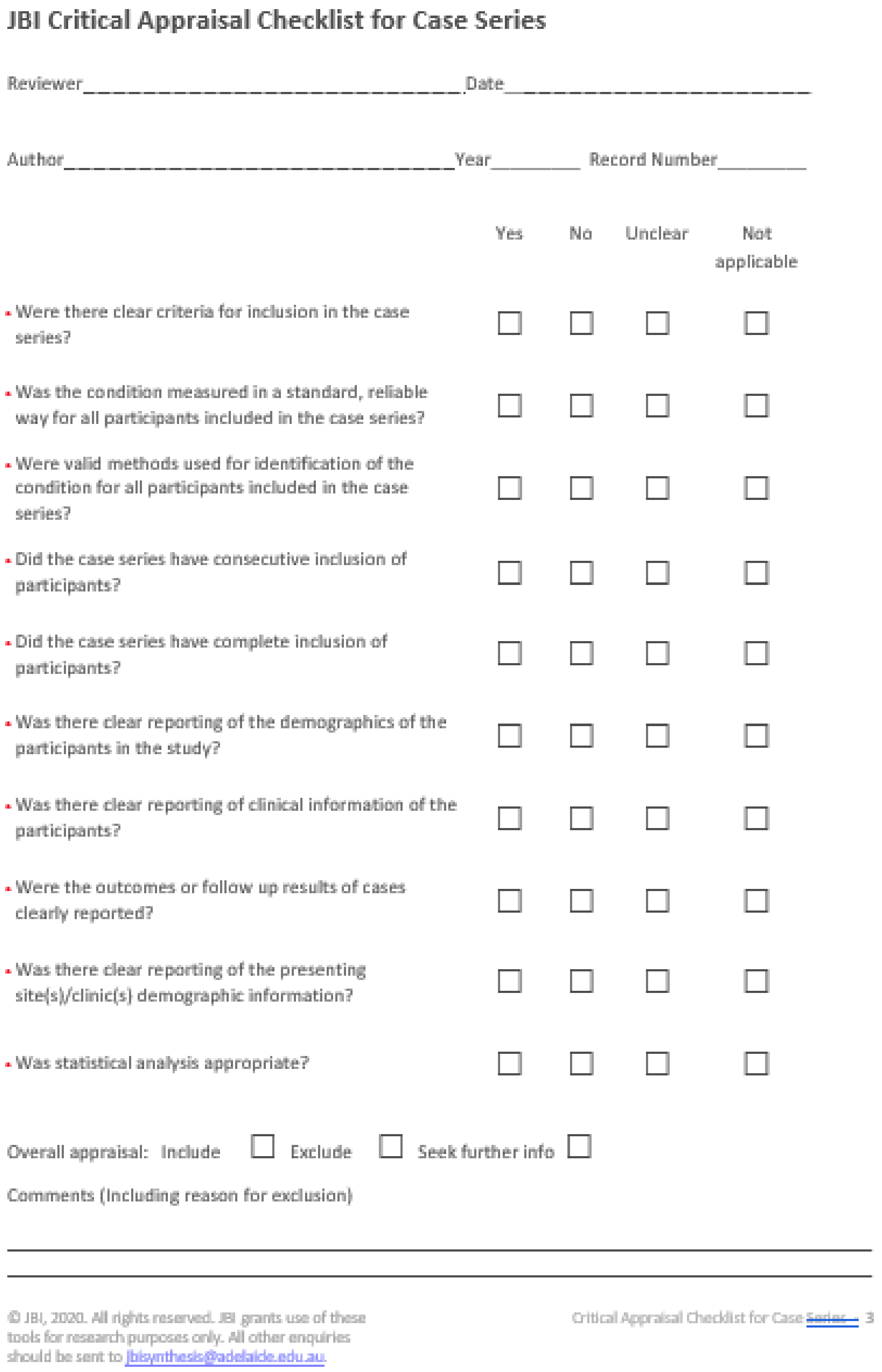
Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

____

____

Figure A2



JBI Critical Appraisal Checklist for Case Series

Reviewer________________________________Date__________________________

Author__________________________________Year_________ Record Number_________

	Yes	No	Unclear	Not applicable
Were there clear criteria for inclusion in the case series?	☐	☐	☐	☐
Was the condition measured in a standard, reliable way for all participants included in the case series?	☐	☐	☐	☐
Were valid methods used for identification of the condition for all participants included in the case series?	☐	☐	☐	☐
Did the case series have consecutive inclusion of participants?	☐	☐	☐	☐
Did the case series have complete inclusion of participants?	☐	☐	☐	☐
Was there clear reporting of the demographics of the participants in the study?	☐	☐	☐	☐
Was there clear reporting of clinical information of the participants?	☐	☐	☐	☐
Were the outcomes or follow up results of cases clearly reported?	☐	☐	☐	☐
Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	☐	☐	☐	☐
Was statistical analysis appropriate?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

____

____

Appendix B

Quality assessment results for included studies using the JBI critical appraisal checklist for studies reporting prevalence data

Authors & Year of publication	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Simeon & Knutelska (2022)	Y	Y	U	Y	Y	Y	Y	Y	Y
Thomson & Jaque (2018)	Y	Y	U	Y	U	Y	Y	Y	Y
Sar et al. (2017)	N	Y	Y	U	U	Y	Y	Y	Y
Lee et al. (2012)	Y	Y	Y	Y	Y	Y	Y	U	N/A
Simeon et al. (1997)	Y	Y	U	Y	Y	Y	Y	Y	Y
Simeon et al. (2001)	Y	Y	U	Y	Y	Y	Y	Y	Y
Simeon et al. (2008)	Y	U	U	U	Y	Y	Y	Y	Y
Simeon, Giesbrecht, et al. (2009)	Y	U	U	N	U	Y	Y	Y	Y

Note. Y-Yes, N-No, U-Unclear, N/A-Not Applicable

Moderate quality – 5-6 items on the checklist marked yes for good quality

Good quality – 7-8 items on the checklist marked yes for good quality

Excellent quality – 9 items on the checklist marked yes for good quality

Appendix C

Quality assessment results for included studies using the JBI critical appraisal checklist for Case Series

Author & Year of publication	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Song et al. (2024)	Y	Y	Y	Y	N	Y	Y	N/A	Y	Y
Michal et al. (2016)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y

Note. Y-Yes, N-No, U-Unclear, N/A-Not Applicable

Moderate quality – 5-6 items on the checklist marked yes for good quality

Good quality – 7-8 items on the checklist marked yes for good quality

Excellent quality – 9-10 items on the checklist marked yes for good quality

Appendix D

Familial and non-familial CTQ-SF

Below are copies of the familial CTQ-SF (Figure D1) and non-familial CTQ-SF (Figure D2) presented to participants.

Figure D1

These questions ask about some of your experiences growing up as a child and a teenager. For each question, select what best describes how you feel. Although some of these questions are of a personal nature, please try to answer as honestly as you can. Your answers will be kept confidential.

Please think only about **family members** when answering the following questions:
When you were growing up -

	Never True	Rarely True	Sometimes True	Often True	Very often True
I didn't have enough to eat.	○	○	○	○	○
I knew that there was someone to take care of me and protect me	○	○	○	○	○
People in my family called me things like "stupid", "lazy", or "ugly".	○	○	○	○	○
My parents were too drunk or high to take care of the family.	○	○	○	○	○
There was someone in my family who helped me feel important or special	○	○	○	○	○
I had to wear dirty clothes.	○	○	○	○	○
I felt loved.	○	○	○	○	○
I thought that my parents wished I had never been born.	○	○	○	○	○

	Never True	Rarely True	Sometimes True	Often True	Very often True
I got hit so hard by someone in my family that I had to see a doctor or go to the hospital.	○	○	○	○	○
There was nothing I wanted to change about my family.	○	○	○	○	○
People in my family hit me so hard that it left me with bruises or mar	○	○	○	○	○
I was punished with a belt, a board, a cord (or some other hard object).	○	○	○	○	○
People in my family looked out for each other.	○	○	○	○	○
People in my family said hurtful or insulting things to me.	○	○	○	○	○
I believe that I was physically abused.	○	○	○	○	○
I had the perfect childhood.	○	○	○	○	○

	Never True	Rarely True	Sometimes True	Often True	Very often True
please select often true for this statement.	○	○	○	○	○
I got hit or beaten so badly that it was noticed by someone like a teacher, neighbor, or doctor.	○	○	○	○	○
Someone in my family hated me.	○	○	○	○	○
People in my family felt close to each other.	○	○	○	○	○
Someone tried to touch me in a sexual way or tried to make me touch them.	○	○	○	○	○
Someone threatened to hurt me or tell lies about me unless I did something sexual with them.	○	○	○	○	○
I had the best family in the world.	○	○	○	○	○
Someone tried to make me do sexual things or watch sexual things.	○	○	○	○	○

	Never True	Rarely True	Sometimes True	Often True	Very often True
Someone molested me (took advantage of me sexually).	○	○	○	○	○
I believe that I was emotionally abused.	○	○	○	○	○
There was someone to take me to the doctor if I needed it.	○	○	○	○	○
I believe that I was sexually abused.	○	○	○	○	○
My family was a source of strength and support.	○	○	○	○	○
please select often true for this statement,	○	○	○	○	○

Figure D2

Please now think only about **people other than family members (e.g., peers, teachers, other adults etc.)** when answering the following questions:
When you were growing up -

	Never True	Rarely True	Sometimes True	Often True	Very often True
I knew that there was someone to take care of me and protect me.	○	○	○	○	○
People called me things like "stupid", "lazy" or "ugly".	○	○	○	○	○
There was someone who helped me feel important and special.	○	○	○	○	○
I felt loved.	○	○	○	○	○
I got hit so hard by someone that I had to see a doctor or go to the hospital.	○	○	○	○	○
Someone hit me so hard that it left me with bruises or marks	○	○	○	○	○
People outside of my family looked out for me.	○	○	○	○	○

	Never True	Rarely True	Sometimes True	Often True	Very often True
People outside of my family said hurtful or insulting things to me.	○	○	○	○	○
please select rarely true for this statement.	○	○	○	○	○
I believe that I was physically abused.	○	○	○	○	○
I got hit or beaten so badly that it was noticed by someone like a teacher, neighbor, or doctor.	○	○	○	○	○
Someone outside of my family hated me.	○	○	○	○	○
Someone tried to touch me in a sexual way or tried to make me touch them.	○	○	○	○	○
Someone threatened to hurt me or tell lies about me unless I did something sexual with them.	○	○	○	○	○

	Never True	Rarely True	Sometimes True	Often True	Very often True
Someone tried to make me do sexual things or watch sexual things.	○	○	○	○	○
Someone molested me (took advantage of me sexually).	○	○	○	○	○
I believe that I was emotionally abused.	○	○	○	○	○
I believe that I was sexually abused.	○	○	○	○	○
Someone outside of my family was a source of strength and support.	○	○	○	○	○
please select rarely true for this statement.	○	○	○	○	○

Appendix E

Quantitative Participant Information Sheet

Below is a copy of the participant information sheet for the quantitative component of the study which was provided to participants prior to interviews taking place.

Individual differences in attachment, adverse childhood experiences and mental health - online survey

Date of approval: 4th July 2023

Invitation to our study

If you are 18 years old or above, we would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear, or you would like more information.

The Present Study

The present study aims to investigate how people's current mental health symptoms may be rooted in their past experiences and relationships with close others.

If you decide to partake in this study, you will be asked to complete an online survey, with questions about yourself and your mental health symptoms, your current experiences of close relationships, any adverse childhood experiences you may have had and how those might still affect you today (post-traumatic stress).

Potential risks

Participating in the current online survey study may be risky for people who have experienced adverse childhood events such as physical or emotional abuse or neglect, and for those suffering from mental health conditions like post-traumatic stress disorder, anxiety, depression, psychosis and dissociation. This is because you are asked to identify any adverse childhood experiences you have had and to indicate how much they may still affect you (post-traumatic stress), in addition to being asked about symptoms of anxiety, depression and dissociation. If you feel that indicating your childhood experiences or mental health symptoms may reduce your wellbeing, please consider carefully whether participating is the right thing for you at this time.

If you participate and you feel affected by the study in any way, you can refer to the mental health services offered by the University of Essex Student Services Hub, located in the Silberrad Student Centre (askthehub@essex.ac.uk or 01206 874000) if you are a student here. Alternatively, please contact your GP or a mental health charity like Mind for support:

Mid and North East Essex Mind

Tel: 01206 764600

mnessexmind.org

Samaritans UK

Tel: 116 123

Trauma Breakthrough

Tel: 01225 984637

https://www.traumabreakthrough.org/contact/

Informed consent

Informed consent will be obtained prior to the experiment online.

Withdrawal

Your participation is voluntary, and you will be free to withdraw from the project at any time without giving any reason and without penalty. If you wish to withdraw during the online survey, simply close your browser. Any incomplete responses will be deleted. After you have completed the experiment, it will not be possible to withdraw because your data is collected anonymously, unless you provide your email address for the prize draw. We reserve the right to not grant credit / prize draw payment for participant who fail attention checks.

Data gathered

- We will collect the following data from each participant:

  - Survey data (demographics, mental health symptoms (depression, anxiety, dissociation), attachment and experiences of close relationships, adverse childhood experiences and post-traumatic stress), email address for entering prize draw (optional).

- We will collect optional email addresses from participants with a diagnosis of depersonalisation-derealisation for a follow-up study.

- We are using your data to understand links between people's past experiences and their current mental health symptoms.

- Your data will be gathered by **name redacted** (principal investigator), **name redacted** (MSc Psychology student) and **name redacted** (DClin Psychology student).

- Your anonymous data may be published in scientific journal articles, and shared in permanent, publicly accessible archives accessible from any country.

- Your anonymous data will be used to complete an MSc student dissertation project and a Clinical Psychology doctorate thesis.

Ethical approval

This project has been reviewed on behalf of the University of Essex Sub-Committee 1 and has been given approval with the following Application ID: ETH2223-1827.

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 the Principal Investigator of the project (see contact details below). If you are still concerned or you think your complaint has not been addressed to your satisfaction, please contact the Director of Research in the Principal Investigator's department (see below).

If you are still not satisfied, please contact the University's Research Governance and Planning Manager (see below).

Contact details

Principal investigator(s)

Name redacted • Reader • Department of Psychology • University of Essex • **Email address redacted**

Co-investigators

Name redacted • MSc Student • Department of Psychology • University of Essex • **Email address redacted**

Name redacted • DClin Psychology Student • School of Health and Social Care • University of Essex • **Email address redacted**

Director of Research, Dept of Psychology

Name redacted (Email address redacted)

University of Essex Research Governance and Planning Manager

Name redacted, Research & Enterprise Office, University of Essex, Wivenhoe Park, CO4 3SQ,

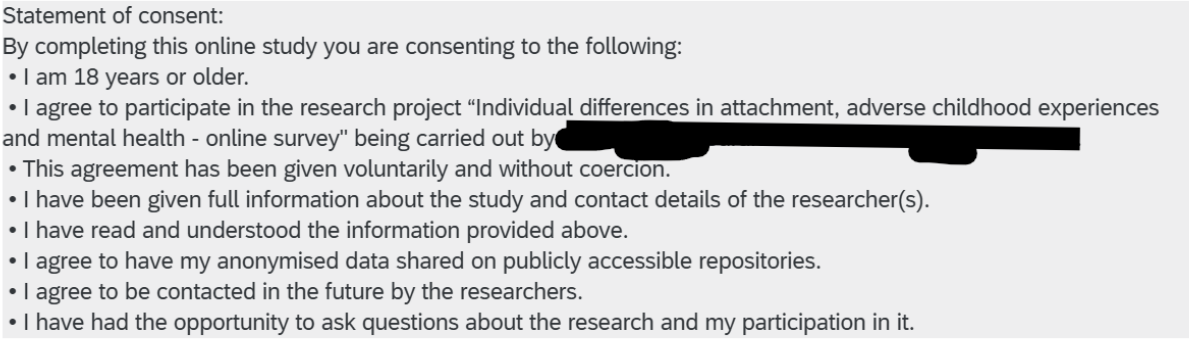
Colchester. Email: **Email address redacted**. Phone: **Phone number redacted**

Appendix F

Statement of Consent

Below is a copy of the statement of consent that was provided to participants prior to completing the online questionnaire in the quantitative component of the study.

Figure F1



Statement of consent:
By completing this online study you are consenting to the following:

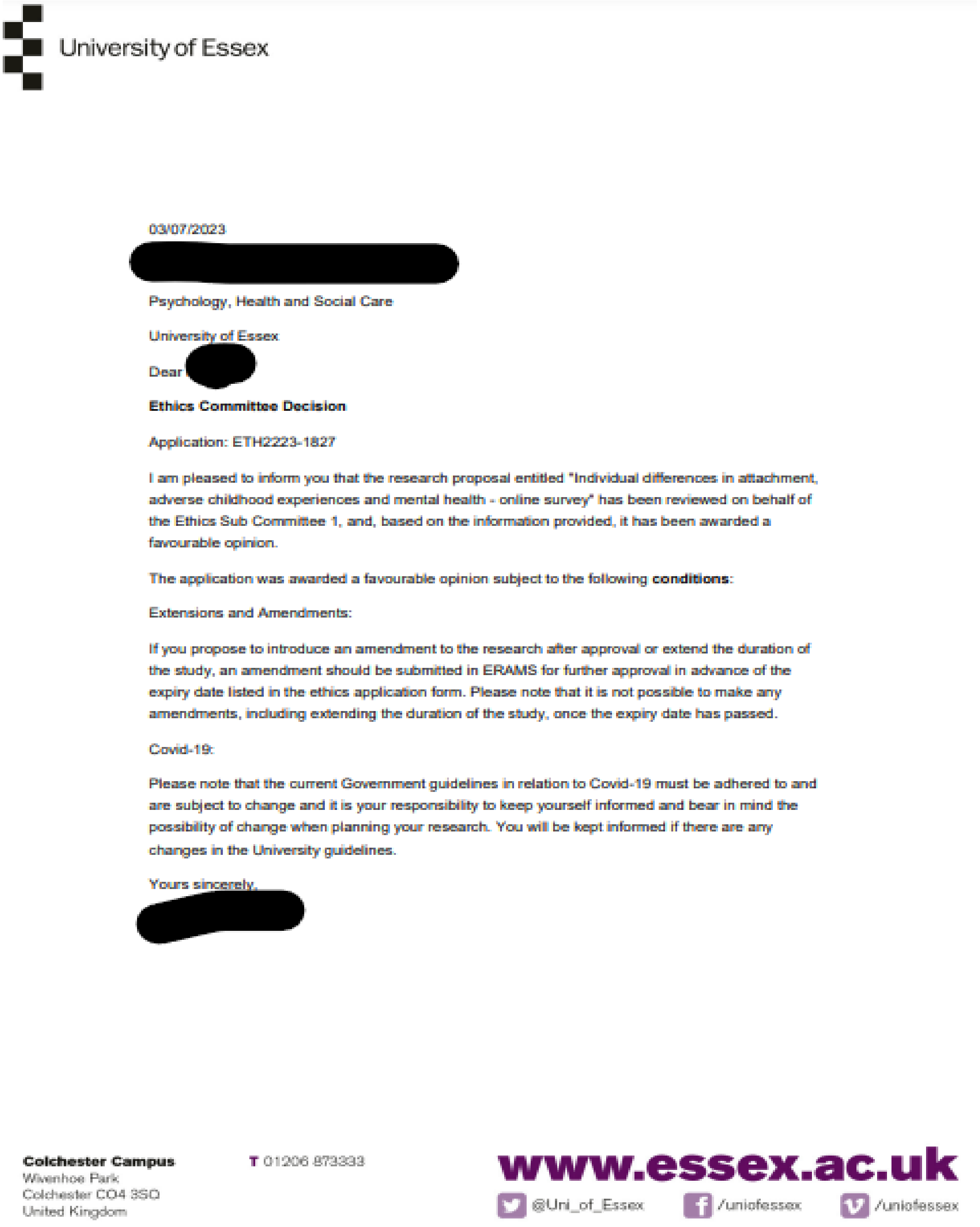
- I am 18 years or older.
- I agree to participate in the research project “Individual differences in attachment, adverse childhood experiences and mental health - online survey" being carried out by [redacted]
- This agreement has been given voluntarily and without coercion.
- I have been given full information about the study and contact details of the researcher(s).
- I have read and understood the information provided above.
- I agree to have my anonymised data shared on publicly accessible repositories.
- I agree to be contacted in the future by the researchers.
- I have had the opportunity to ask questions about the research and my participation in it.

Appendix G

University Ethical Approval

Below are copies of the ethical approval certificate. The quantitative component approval is copied in Figure E1. The qualitative component approval is copied in Figure E2.

Figure G1



University of Essex

03/07/2023

[redacted]

Psychology, Health and Social Care

University of Essex

Dear [redacted]

Ethics Committee Decision

Application: ETH2223-1827

I am pleased to inform you that the research proposal entitled "Individual differences in attachment, adverse childhood experiences and mental health - online survey" has been reviewed on behalf of the Ethics Sub Committee 1, 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.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

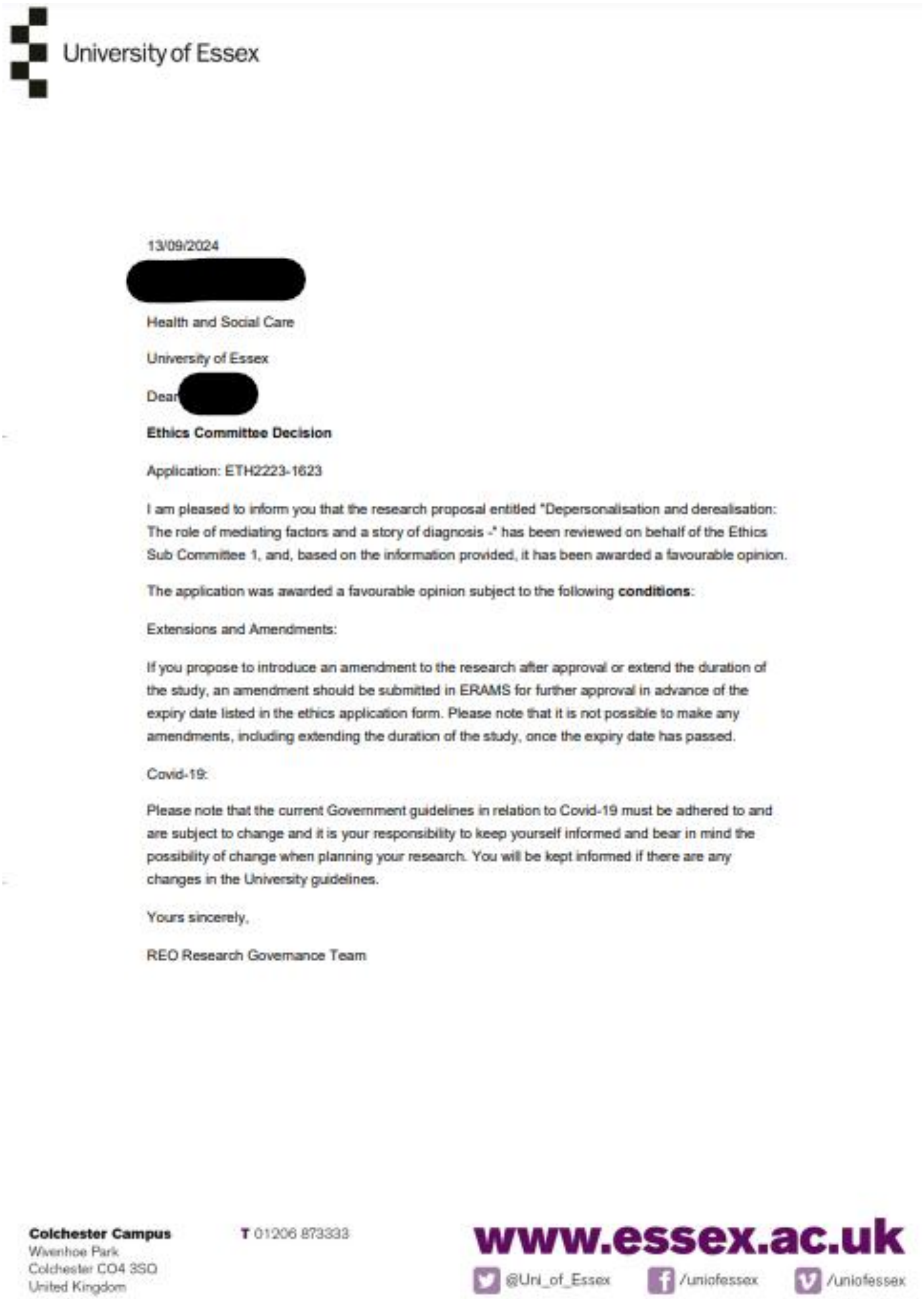
[redacted]

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

www.essex.ac.uk
@Uni_of_Essex
/uniofessex
/uniofessex

Figure G2



University of Essex

13/09/2024

[redacted]

Health and Social Care

University of Essex

Dear [redacted]

Ethics Committee Decision

Application: ETH2223-1623

I am pleased to inform you that the research proposal entitled "Depersonalisation and derealisation: The role of mediating factors and a story of diagnosis -" has been reviewed on behalf of the Ethics Sub Committee 1, 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.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance Team

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

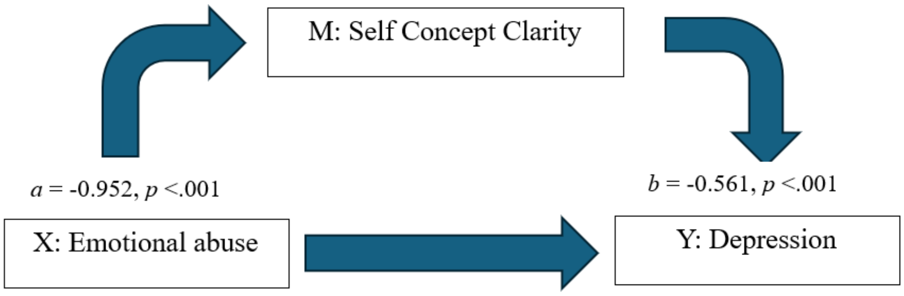
www.essex.ac.uk
@Uni_of_Essex /uniofessex /uniofessex

Appendix H

Mediation Analyses for emotional abuse, emotional neglect, physical neglect and depression

Below are diagrams of the mediation analyses for emotional abuse, emotional neglect, physical neglect and depression.

Figure H1

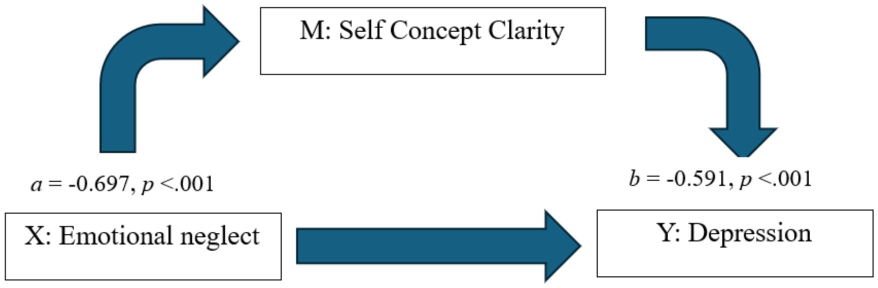


Direct effect, $c' = 0.342$, $p=.002$

Total effect, $c = 0.890$, $p < .001$

Indirect effect, $B = 0.534$, $p < .001$, 95% CI [0.322, 0.746]

Figure H2

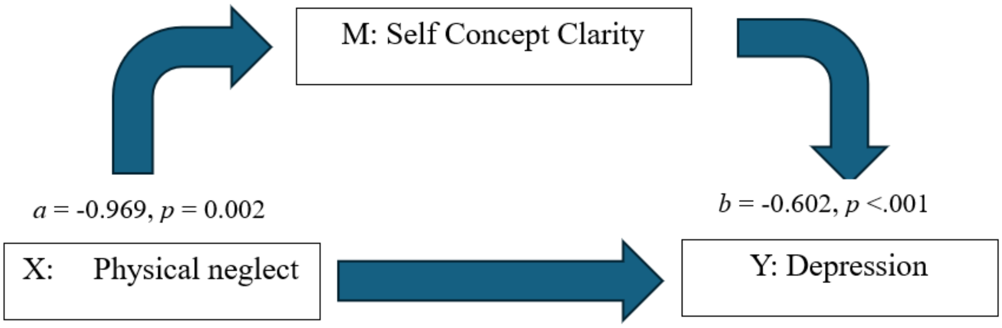


Direct effect, $c' = 0.278$, $p=.001$

Total effect, $c = 0.708$, $p < .001$

Indirect effect, $B = 0.412$, $p<.001$, 95% CI [0.190, 0.634]

Figure H3



Direct effect, c' = 0.434, p = .016

Total effect, c = 1.042, p<.001

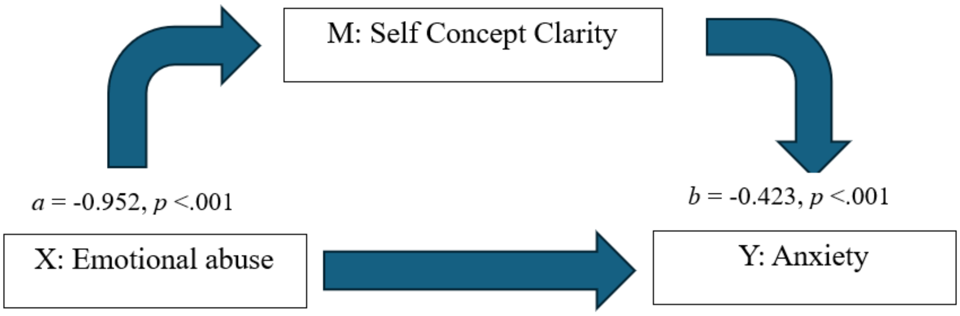
Indirect effect, B = 0.583, p = .003, 95% CI [0.202, 0.965]

Appendix I

Mediation Analyses for emotional abuse, physical neglect and anxiety

Below are diagrams of the mediation analyses for emotional abuse, physical neglect and anxiety.

Figure I1

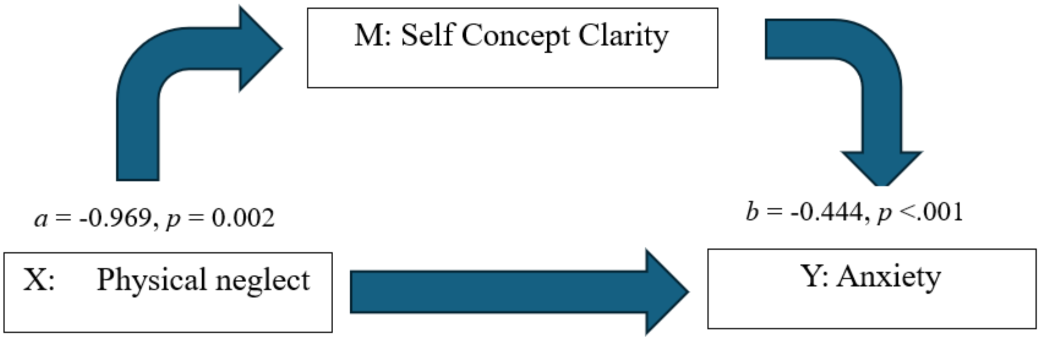


Direct effect, *c'* = 0.261, *p*=.033

Total effect, *c* = 0.668, *p* < .001

Indirect effect, *B* = 0.403, *p* < .001, 95% CI [0.224, 0.581]

Figure I2



Direct effect, *c'* = 0.470, *p* = .015

Total effect, *c* = 0.910, *p*<.001

Indirect effect, *B* = 0.430, *p* = .004, 95% CI [0.138, 0.722]

Appendix J

Interview Guide

Below is a copy of the interview guide used for the interviews as part of the qualitative component of the study. Proposed questions were split into three sections which focused on participants' experiences of DPDR, their journey to a diagnosis and their hopes for the future related to the condition. Proposed questions are highlighted in bold whilst prompts are italicised. Each initial question for the set was followed by a set of prompt questions. The questions in the prompt sections were asked based on the interviewee's responses but typically the majority of prompt questions were asked.

Question set 1 (experiences of DPDR)

I would like you to tell me a little bit about your experience of depersonalisation derealisation disorder (DPDR)?

Question set 1 prompts

When did you first notice experiences where you didn't feel real/the world didn't feel real?

What was your life like around this time?

Can you tell me about your childhood? (areas of exploration will include experience of growing up, household, school, bereavements, abuse, mental health difficulties during childhood)

Can you tell me what it is like to feel like the world/you are not real?

Are these experiences ongoing?

How do you cope with these experiences?

Tell me about your sense of self. Do you have a clear sense of who you are/your identity?

How was your sense of self affected by abuse/neglect/early childhood experiences?

Question set 2 (journey to diagnosis)

Can you tell me more about your diagnosis of DPDR?

Question set 2 prompts

How old were you when you received your diagnosis?

Can you tell me about your journey to receiving a diagnosis? (areas of exploration will include how long it took to receive a diagnosis, how many different healthcare providers they consulted, who provided the diagnosis, any other mental health diagnoses and if so age of this)

What were your experiences of DPDR like around the time of diagnosis? (was this different from prior to diagnosis?)

What did it mean to you to receive a diagnosis of DPDR? (explore impact and if it has caused any change positive or negative for example treatment access)

Are there any factors that you think might have prevented you from receiving an earlier diagnosis?

What helped you to receive a diagnosis of DPDR?

Where do you think you are now on this journey?

Question set 3 (future)

Having received a diagnosis of DPDR can you tell me about your hopes for the future?

Question set 3 prompts

How are you feeling about your future with a diagnosis of DPDR?

How do you feel about the future?

Is there something that you would like to see changed in the healthcare system to support diagnoses of DPDR?

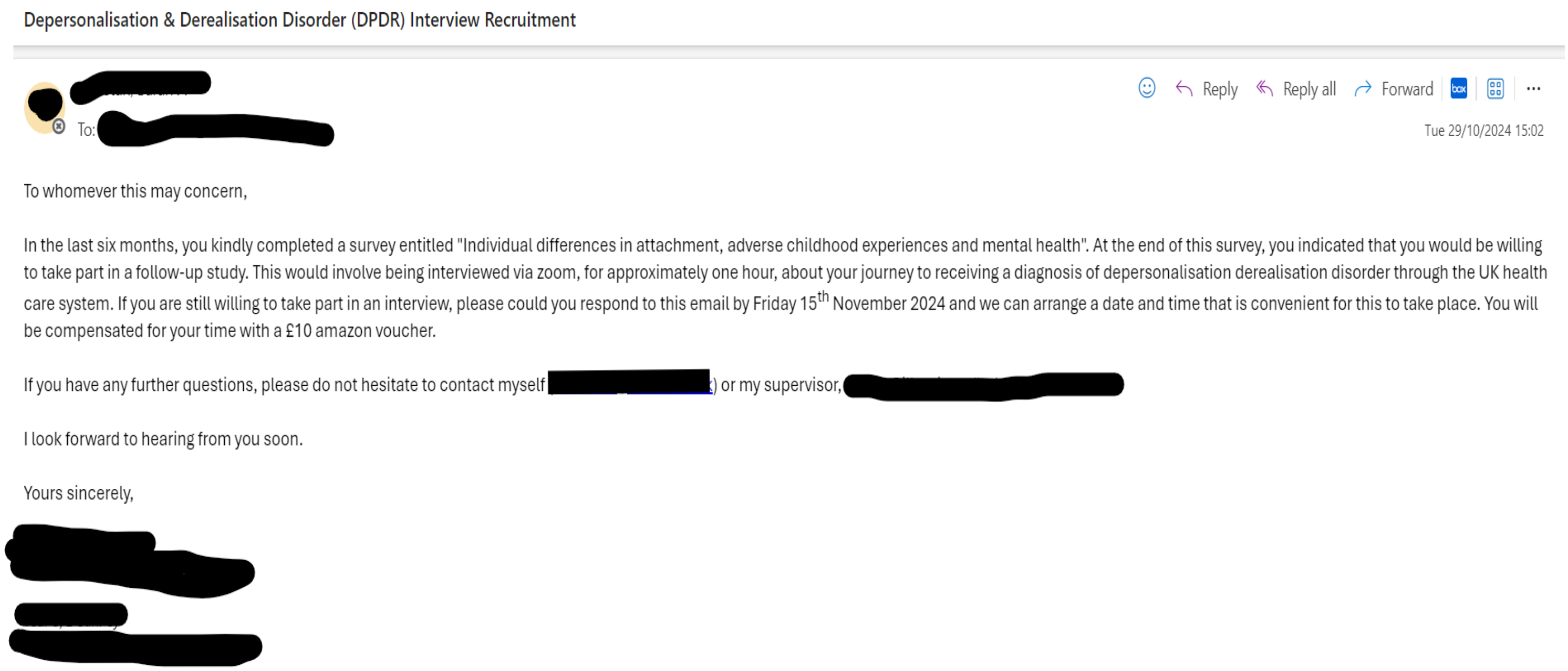
If a friend was starting the journey to diagnosis for DPDR, what would you hope might be different for them?

Appendix K

Example recruitment email for qualitative component of study

Example email sent to participants requesting participation in the qualitative component of the study.

Figure K1



Depersonalisation & Derealisation Disorder (DPDR) Interview Recruitment

[redacted]
To: [redacted]

Tue 29/10/2024 15:02

To whomever this may concern,

In the last six months, you kindly completed a survey entitled "Individual differences in attachment, adverse childhood experiences and mental health". At the end of this survey, you indicated that you would be willing to take part in a follow-up study. This would involve being interviewed via zoom, for approximately one hour, about your journey to receiving a diagnosis of depersonalisation derealisation disorder through the UK health care system. If you are still willing to take part in an interview, please could you respond to this email by Friday 15th November 2024 and we can arrange a date and time that is convenient for this to take place. You will be compensated for your time with a £10 amazon voucher.

If you have any further questions, please do not hesitate to contact myself [redacted]) or my supervisor, [redacted]

I look forward to hearing from you soon.

Yours sincerely,

[redacted]

[redacted]

Appendix L

Participant Information Sheet

Below is a copy of the participant information sheet for the qualitative component of the study which was provided to participants prior to interviews taking place.

Participant Information Sheet

Project title

Depersonalisation and derealisation: The role of mediating factors and a story of diagnosis

Invitation paragraph

My name is **name redacted** and I am a Trainee Clinical Psychologist at the University of Essex. I would like to invite you to take part in a research study. Before you decide whether or not to take part, 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 about.

What is the purpose of the study?

Depersonalisation-Derealisation (DP-DR) is a type of dissociative disorder. Depersonalisation and derealisation experiences only started to be recognized as distinct features of a dissociative disorder in the DSM-5 published in 2013. The research field about this disorder is still developing and there is still a lot to be understood. Some concerns exist about the quality of diagnosis for DP-DR and research suggest that it is an underdiagnosed phenomenon. This study hopes to add to the field of literature on DP-DR, supporting mental health professionals to understand who might be more prone to experience depersonalization and derealisation and the factors that might affect this experience. This study aims to interview you about your experience of DP-DR and understand more about your journey to a diagnosis of DP-DR.

.

You will be asked to participate in an interview about your journey to a diagnosis of DP-DR. The interview will last approximately an hour. It will take place virtually via Microsoft Teams or Zoom, dependent on your preference.

Data collection will be taking place until Friday 31st January 2025. Data analysis will begin following the completion of your interview. Final submission of the project to the University of Essex DClinPsy is due in April 2025.

Why have I been invited to participate?

You have been invited to participate in this project following your participation in a previous online survey entitled “Individual difference in attachment, adverse childhood experiences and mental health”. You indicated that you were interested in participating in a follow up interview to understand more about your journey to receiving a diagnosis through the UK health care system.

Do I have to take part?

Taking part in this research is entirely voluntary. If you do decide to take part you will be asked to provide consent before engaging in the interview. You have the right to withdraw without explanation or penalty however, once the data has been analysed it will not be possible to withdraw your data due to it being anonymised. A decision to participate or not will have no impact on any care or support you may be receiving.

If you wish to withdraw, please contact (name removed) at (email address removed) quoting your pseudonym. All your data will be destroyed prior to analysis.

What will happen to me if I take part?

If you are willing to take part you will be asked to indicate your consent. You will then receive an email link for the interview. Interviews will take place on either Zoom or Microsoft Teams (depending on your preference) and will be conducted by (name removed). They will be recorded and transcribed using the programme’s recording function. They will be saved on an encrypted hard drive and only available to (name removed). The interviews will be an opportunity to discuss your experiences of DP-DR and your journey to diagnosis. The interview will last approximately an hour but this may be shorter or longer dependent on how much you expand on your experiences. Following transcription of your data, you will be given a pseudonym to ensure that your information remains unidentifiable. Any quotes used in the write up of the study will be attributed to the pseudonym.

To thank you for your time you will be given a £10 amazon voucher following completion of the interview.

What are the possible disadvantages and risks of taking part?

It is possible that you may be distressed by the questions asked in the interview which could trigger some traumatic memories or an episode of depersonalisation or derealisation. The interviewer is a Trainee Clinical Psychologist and will support you to use grounding techniques to re-orientate you to the present moment if distressed. A discussion can take place prior to the interview to ensure that there is a method for you to communicate to the interviewer if you are feeling distressed. If you are feeling too distressed, overwhelmed, or finding the conversation upsetting, you are free to take a break or terminate the interview and withdraw your data from the study. A debrief will also be provided with the interviewer at the completion of the interview and you will be offered details of further support services if needed. You may also wish to have the details of your current healthcare provider to hand, to contact them in case of distress.

You may be concerned that comments you make will be attributed back to you or could affect care that you are receiving. All information including comments you make will be anonymised via the use of a pseudonym and therefore will not be identifiable. The study does not have any direct links with any services that might be supporting you and so this will not affect any care you are receiving. If the interviewer has any concerns about your immediate safety, they may be obliged to contact emergency services for further support. You will be informed if this is the case.

As the interviews will be taking place via a computer screen there is a risk of screen fatigue. If you feel that you require a break from the computer screen. Please inform the interviewer and this will be facilitated.

What are the possible benefits of taking part?

By participating in this study, you will be contributing to increased understanding of the dissociative disorder DP-DR. You will also be informing mental health professionals about the journey to a diagnosis. It is hoped that this will support mental health professionals to better understand and diagnose DP-DR.

What information will be collected?

You will be asked to provide your name for the consent form. Other demographic information will have already been collected during the earlier study on individual differences in attachment, adverse childhood experiences and mental health. You will be asked about your experiences of DP-DR and your journey to a diagnosis. Your data will be gathered by **name redacted**.

You will also be asked for your current location. This is to ensure that if emergency services were needed, the interviewer could direct them to the appropriate location to give you support. If you do not wish to provide this information, you can let the interviewer know prior to the interview. The information regarding your current location will be destroyed, immediately after the interview has taken place.

Will my information be kept confidential?

Any identifiable data will be kept confidential and only accessible to the Principal Investigator **name redacted** and the primary supervisor **name redacted**. The secondary supervisor **name redacted** will have access to anonymised data but no identifiable information will be included.

Any identifying information within the interview will be anonymised.

Your data will be stored on an encrypted hard drive, only available to members of the research team. All identifiable data will be kept password protected and only members of the research team directly involved will have access to this password.

The interviews will be recorded and transcribed via zoom or Microsoft Teams and will also be stored on an encrypted hard drive. Only the Principal Investigator will have access to the recorded interviews. The primary and secondary supervisor may have access to transcripts of the interviews.

Your data will be retained for the duration of the study. Research data will be made available for access and re-use where legally, ethically and commercially appropriate, taking note of any relevant safeguards. The transcripts of your interviews may be deposited in a research data repository. Any non-anonymised data will be destroyed at the completion of the study. Anonymised data will be permanently archived at the point of publication. Interview recordings will be automatically deleted by zoom or Microsoft Teams after one year.

What is the legal basis for using the data and who is the Data Controller?

The legal basis for using your data will be obtaining informed consent.

The Data Controller is the University of Essex and the contact is, University Information Assurance Manager (dpo@essex.ac.uk).

What should I do if I want to take part?

If you wish to take part, please provide written consent on the attached consent form that you have received. Please return this via email to **name redacted** at **email address redacted**. You will then be contacted by **name redacted** to arrange a convenient date and time for interview.

What will happen to the results of the research study?

The results of the study will be used for a doctoral thesis and may be published in a journal article or some other similar format. It is intended that the results of this study will 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 **name redacted** at **email address redacted**.

Who is funding the research?

This research is not being funded.

Who has reviewed the study?

The University of Essex Ethics Sub-Committee 1 has approved this application.

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 the principal investigator of the project, **name redacted** at **email address redacted** or her supervisor, **name redacted** at **email address redacted**. If you are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact the departmental Director of Research in the department responsible for this project, **name redacted** at **email address redacted**. If you are still not satisfied, please contact the University of Essex Research Integrity Manager, **name redacted** at **email address redacted**. Please include the ERAMS reference which can be found at the foot of this page.

Name of the Researcher/Research Team Members

Principal Investigator

Name: **name redacted**

Status: Trainee Clinical Psychologist

Department: Health and Social Care, University of Essex

Email: **email address redacted**

Primary Supervisor

Name: **name redacted**

Department: Psychology and Centre for Brain Science, University of Essex

Email: **email address redacted**

Secondary Supervisor

Name: **name redacted**

Status: Clinical Psychologist

Department: Health and Social Care, University of Essex

Email: **email address redacted**

If you have been affected by any of the issues raised from participating in this study, please see the following information below.

If you have been affected by any of the issues raised from participating in this study, please see the following information below.

INFORMATION LEAFLET

On support services available if you feel affected

by any issues raised from participating in the study

Everyone may feel upset or distressed. These emotions are natural reactions to disappointment or apprehension. However, if you think your mood has been low for some time and is affecting your ability to cope with day-to-day life, you should contact your GP or counselling services and/or seek help and advice from professional organisations. Some of these organisations are listed below:

NHS Direct

The National health services dedicated 24hr helpline, with a qualified nurse or health practitioner at the end of the phone to answer any questions or to promote advice.

Tel. 0845 4647 (24hrs); website www.nhsdirect.nhs.uk

MIND

Leading mental health charity in England and Wales. The Mind*Info* Line offers thousands of caller's confidential help on a range of mental health issues.

15-19 Broadway, London E15 4BQ

Tel. 0845 766 0163; website: www.mind.org.uk

MENTAL HEALTH FOUNDATION

Independent organisation that helps people to survive, recover from and prevent mental health problems

9th floor, Sea Containers House, 20 Upper Ground, London SE19QB

Tel. 020 78031100; website: www.mentalhealth.org.uk

This is the biggest website on mental health (and mental illness) in the UK.

Samaritans

National organisation offering support to those in distress who feel suicidal or despairing and need someone to talk to.

The telephone number of your local branch can be found in the telephone directory.

The 24-hour Helpline: 08457 90 90 90; website: www.samaritans.org.uk

Depression Alliance

Information, support and understanding for people who suffer with depression and for relatives who want to help.

35 Westminster Bridge Road, London SE1 7JB

Tel: 0845 123 23 20; website: www.depressionalliance.org/

Fellowship of Depressives Anonymous

A national mutual support group for people suffering from Depression

Box FDA, Self-Help Nottingham, Ormiston House, 32-36 Pelham Street, Nottingham

NG1 2EG Tel: 0870 774 4320; website: www.depressionanon.co.uk

UNREAL

Information, support and understanding for people with a lived experience of DP-DR, and their carers and families

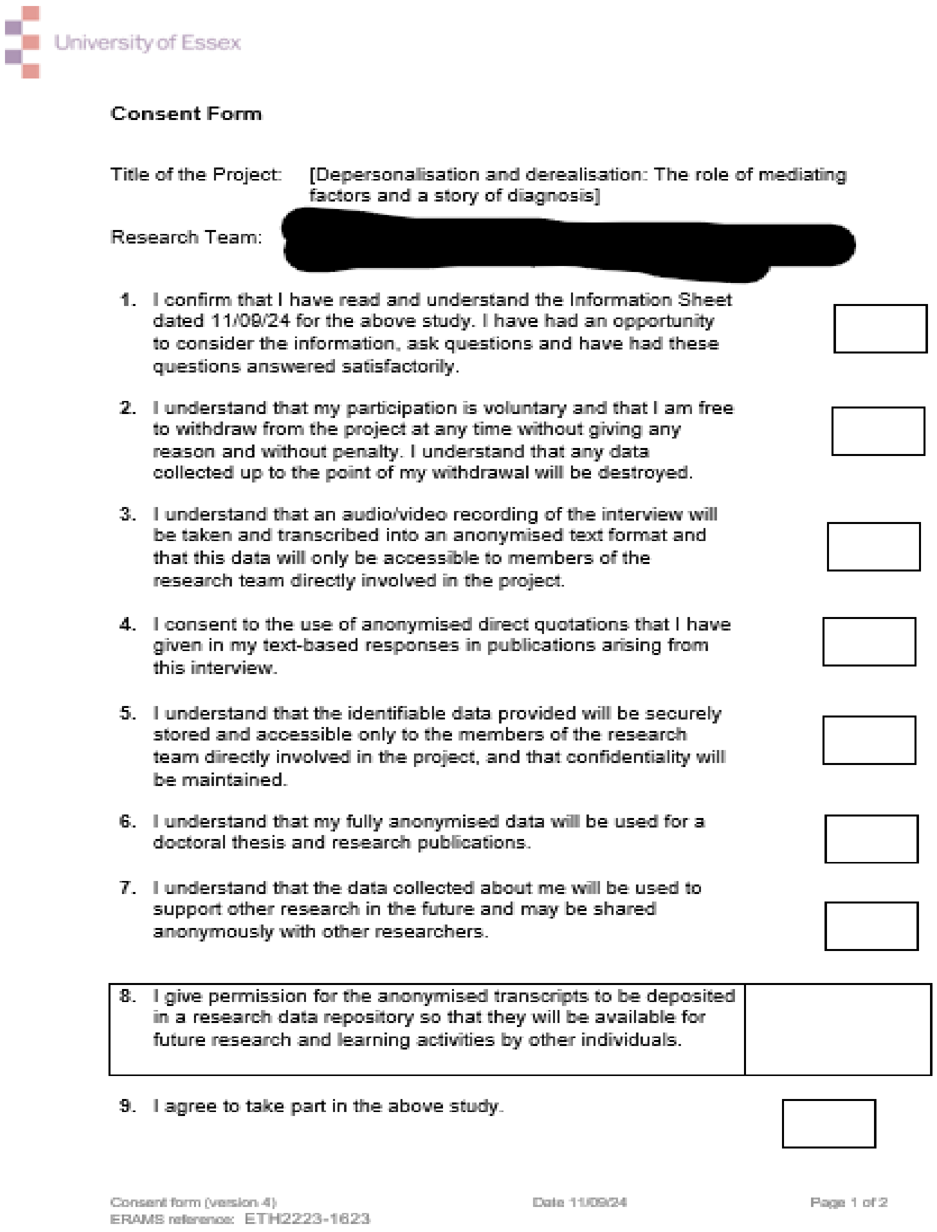
website: www.unrealuk.org

Appendix M

Consent Form

Below is a copy of the consent form for the qualitative component of the study. Participants were asked to provide consent prior to the study.

Figure M1



University of Essex

Consent Form

Title of the Project: [Depersonalisation and derealisation: The role of mediating factors and a story of diagnosis]

Research Team: [redacted]

1. I confirm that I have read and understand the Information Sheet dated 11/09/24 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. I understand that any data collected up to the point of my withdrawal will be destroyed. ☐
3. I understand that an audio/video recording of the interview will be taken and transcribed into an anonymised text format and that this data will only be accessible to members of the research team directly involved in the project. ☐
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 anonymised transcripts to be deposited in 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. ☐

Consent form (version 4) Date 11/09/24 Page 1 of 2
ERAMS reference: ETH2223-1623

Appendix N

Debrief Information Sheet

Below is a copy of the debrief information sheet given to participants after completion of the interview.

Debrief Sheet

Project title

Depersonalisation and derealisation: The role of mediating factors and a story of diagnosis

Thank you

Thank you for taking part in this study. Now that you have completed your tasks, I would like to take this opportunity to remind you of the following:

1) **Data Anonymity and storage**
    - The data you have provided will be anonymised and stored on an encrypted hard drive, for a minimum of 3 years, after which time it will be destroyed under secure conditions.
    - The data will be included in a write-up as part of a doctoral thesis and therefore anonymised data will be made available to those marking the project.
    - The data may be published publicly as part of a write up of the study. However, all data published will be anonymised.
2) **Right to withdraw**
    - You are free to withdraw at any stage prior to analysis without giving a reason. A decision to withdraw, or a decision not to take part at all, will not affect any treatment/care that you may be receiving (should this be relevant).
    - Should you wish to withdraw you can contact the Principal Investigator, **Name redacted** or the Project Supervisor, **Name redacted**. Contact details to do this can be found in point 4.
    - Please make sure that you state the participant number or pseudonym you were given at the start of the study, if you do wish to withdraw as all data will have been anonymised.
3) **Findings of the study**

- If you are interested in receiving the findings of the study, please contact the Principal Investigator, **Name redacted** or the Project Supervisor, **Name redacted**. Contact details to do this can be found in point 4.

4) **Contact Details**

Principal Investigator
Name: **Name redacted**
Status: Trainee Clinical Psychologist
Department: Health and Social Care, University of Essex
Email: **Email address redacted**

Primary Supervisor
Name: **Name redacted**
Department: Psychology and Centre for Brain Science, University of Essex
Email: **Email address redacted**

Secondary Supervisor
Name: **Name redacted**
Status: Clinical Psychologist
Department: Health and Social Care, University of Essex
Email: **Email address redacted**

Appendix O

Interview Transcript

Below is a copy of one of the interview transcripts. This interview took place with Taylor.

DPDR Interview 8 – Taylor

1

00:00:01.870 --> 00:00:04.930

Sarah: Right, is that okay on your end?

Taylor: Yeah

2

00:00:05.290 --> 00:00:08.140

Sarah: Great! Okay, so

3

00:00:08.300 --> 00:00:27.539

Sarah: the first question I'm going to start with might feel a little bit big. So I just want to say if if it does, and you're not really sure where to start, please do ask me to break it down, that's absolutely fine. But I wondered if you could tell me a little bit about your experience of depersonalisation derealisation disorder.

4

00:00:28.990 --> 00:00:29.900

Taylor: So (clears throat),

5

00:00:33.060 --> 00:00:37.370

Taylor: I started therapy, it'll be two years ago now,

6

00:00:38.140 --> 00:00:47.919

Taylor: cause I had all sorts of kind of issues I suppose and through that, that's when, like talking to my therapist, I realised it wasn't kind of normal (makes quotation marks with fingers in air" what I was

7

00:00:48.400 --> 00:01:00.490

Taylor: feeling. So I took … I spoke to her about feeling like a robot and everything (waves hand in front of face) kind of through a pane of glass and and a numbness (holds chest when saying the word numbness)

8

00:01:01.371 --> 00:01:08.200

Taylor: and she kind of interrogated that more and more and kind of said "that's not, you know,

9

00:01:08.430 --> 00:01:12.900

Taylor: you you shouldn't be experiencing" or, you know, "not everyone experiences that."

10

00:01:13.300 --> 00:01:16.809

Taylor: So that's when I kind of realised that it wasn't …

11

00:01:17.140 --> 00:01:21.136

Taylor: it was (emphasises the word was) something, cause I'd got so used to feeling it that ...

12

00:01:22.000 --> 00:01:33.999

Taylor: I just thought that was normal or normal for me and so I hadn't really kind of thought about it much but through kind of working through other (gestures with hands to illustrate point) issues with her, we kind of got to, "oh, yeah",

13

00:01:34.260 --> 00:01:41.130

Taylor: that's that's another kind of symptom of what's (gestures with hands to illustrate point) … (interrupts self) I had like trauma from childhood. That's another way that you kind of,

14

00:01:41.230 --> 00:01:45.529

Taylor: not coping with it, but kind of another symptom of what's going on.

15

00:01:47.130 --> 00:02:04.220

Taylor: So yeah. So I've then just been kind of unpacking (gestures with hands to illustrate point) it with her for the past … that was probably a year ago that we kind of got to that point and so the past year, just unpacking that. She wasn't an expert in DPDR, so she she reports into a … I think he's a clinical psychologist or psychiatrist

16

00:02:04.260 --> 00:02:10.079

Taylor: and he is (gestures with hands to illustrate point) an ex… bit more of an expert in it. So he's been like supporting her in my like journey of

17

00:02:10.520 --> 00:02:12.013

Taylor: exploring it.

18

00:02:12.780 --> 00:02:17.009

Taylor: And then I have, I have mentioned it to my GP.

19

00:02:18.178 --> 00:02:20.172

Taylor: They were quite dismissive (laughs)

20

00:02:21.320 --> 00:02:27.710

Taylor: and kind of, I think because I'm seeing my (gestures with hands to illustrate point) therapist privately, they were kind of like, I don't really wanna go near this

21

00:02:27.820 --> 00:02:33.449

Taylor: unless you're telling me you're having like suicidal (gestures with hands to illustrate point) thought … you know if it's something really like intense. So,

22

00:02:34.116 --> 00:02:41.850

Taylor: I've kind of just left (gestures with hands to illustrate point) it with my GP and continued on with my therapist cause that has been helping basically, so yeah.

23

00:02:42.300 --> 00:02:51.019

Sarah: Thank you, and when did you first notice experiences of depersonalisation and derealisation?

24

00:02:51.020 --> 00:03:01.969

Taylor: So we can't pinpoint when it kind of started for me. The fir… the first time it was really (gestures with hands to illustrate point) noticeable was when I got married in 2018

25

00:03:02.200 --> 00:03:17.419

Taylor: and that whole day I kind of … (waves hand over face to illustrate blacking out) I black blacked out, and I was numb on the day, and that caused me a lot of distress following that day cause it was supposed to be a really happy day but I can't really remember it and what I can remember, I just remember being completely (gestures with hands to illustrate point) numb.

26

00:03:18.072 --> 00:03:22.540

Taylor: Like it … like I … and when I … the memories of it, it's like I'm watching (gestures with hands to illustrate point) someone else (laughs).

27

00:03:22.620 --> 00:03:25.440

Taylor: It happened to someone else. So that was kind of the first

28

00:03:25.600 --> 00:03:34.350

Taylor: significant one, but I think it was (gestures with hands to illustrate point) before that as well, as in day to day things that have caused me kind of stress (gestures with hands to illustrate point) and made me feel …

29

00:03:35.060 --> 00:03:37.869

Taylor: I feel like it's been weaving (gestures with hands to illustrate point) in and out of like

30

00:03:38.090 --> 00:03:43.540

Taylor: my life for probably a d… a good decade but there's no like significant

31

00:03:44.814 --> 00:03:49.790

Taylor: (gestures with hands to illustrate point) moment other than I I properly remember it happening when I got married, yeah.

32

00:03:50.709 --> 00:03:57.159

Sarah: Mmm mmm, and is it something that is like chronic for you and is there…

Taylor: (interrupting interviewer) Yeah

Sarah: …all the time? Yeah (nods head)

33

00:03:57.210 --> 00:04:03.679

Taylor: Yeah, I mean (gestures with hands to illustrate point), so I'm, I'd say I'm I'm getting better now, but a year ago yes, it was chronic.

34

00:04:04.155 --> 00:04:12.800

Taylor: Like it wouldn't be set (gestures with hands to illustrate point) kind of like an hour or something. It could be weeks (gestures with hands to illustrate point) where I just … that's that's (gestures with hands to illustrate point) like my mode of …

35

00:04:13.638 --> 00:04:16.031

Taylor: that's how I operated.

36

00:04:17.240 --> 00:04:31.169

Taylor: Whereas now a year (gestures with hands to illustrate point) on, I'd say I I've I've done a lot of work to kind of work out what my triggers are or to notice when it's happening. So it sent … it seems to be more now around specific events or

37

00:04:31.673 --> 00:04:39.539

Taylor: if I'm already kind of a (gestures with hands to illustrate point) really stressed and I can, I can notice it more now, whereas previously (gestures with hands to illustrate point)

38

00:04:39.660 --> 00:04:44.110

Taylor: it was just happening all the time (laughs) or or for long (gestures with hands to illustrate point) periods of time anyway.

39

00:04:46.900 --> 00:04:51.919

Sarah: Mmm, mmm, mmm (nods head), so (makes noise with mouth whilst searching for words) what do you feel like

40

00:04:52.160 --> 00:04:59.069

Sarah: has changed more recently, that you think might have changed kind of the way you're experiencing it?

41

00:04:59.290 --> 00:05:03.947

Taylor: Yeah, I think because of what I'm doing in therapy, a greater awareness of (gestures with hands to illustrate point) …

42

00:05:04.460 --> 00:05:09.100

Taylor: well, dealing with stuff from childhood, like traumatic events.

43

00:05:09.390 --> 00:05:30.819

Taylor: I've got (gestures with hands to illustrate point), I'm currently going through a separation with my husband and part of it is just dealing (gestures with hands to illustrate point) with, like learning to look after myself again, as an adult (laughs). So what has changed is more … I've got more awareness and lots (gestures with hands to illustrate point) of things about like who I am (points to self), how I feel and why I kind of behave the way I behave. Like what thing… what actions am I taking (gestures with hands to illustrate point), w… you know,

44

00:05:30.960 --> 00:05:41.970

Taylor: when I feel down, or when I feel out of control or stress (gestures with hands to illustrate point), what am I doing in those moments? So it's kind of a lot (gestures with hands to illustrate point) of change in my life and also a lot of change in

45

00:05:42.030 --> 00:05:45.735

Taylor: the way I'm behaving but a lot of it is around just awareness

46

00:05:46.558 --> 00:05:56.010

Taylor: and noticing what I'm (gestures with hands to illustrate point) doing and how it, how it makes me feel rather than just ignoring it and then that's when I tend (gestures with hands to illustrate point) to just flip into default like just cut (used hands to demonstrate cutting out) out.

47

00:05:56.290 --> 00:06:05.519

Taylor: Whereas that was obviously, it was making me really sad, cause I've got a daughter and I was like, I can't (gestures with hands to illustrate point) remember big parts of her childhood so far, cause I've just switched (slaps hand into palm of other hand) off

48

00:06:05.700 --> 00:06:08.891

Taylor: or I've just held (gestures with hands to illustrate point) her at arm's length.

49

00:06:09.930 --> 00:06:20.639

Taylor: So a lot of it has been like, I don't want to live like that and I don't want her to have a a mother that is, you know, distant from her. So yeah, that's kind of what's changed.

50

00:06:21.080 --> 00:06:26.039

Sarah: Mmm, I just wanna pick up on you having your daughter as well.

51

00:06:26.040 --> 00:06:26.700

Taylor: Yeah.

52

00:06:29.120 --> 00:06:41.660

Sarah: And I'm just wondering, like what your … what you remember about kind of your pregnancy and and like birth of of her as well, do you remember much?...

Taylor: (interrupting and speaking over interviewer) Yeah

Sarah: …What's that been like?

53

00:06:42.030 --> 00:06:53.980

Taylor: It was, it was lonely. I had a lot of complications and then I had to have a planned C-section. I took it all on myself and again ve… very (gestures with hands to illustrate point) inward. I d… I wouldn't (shakes head) accept any help.

54

00:06:54.908 --> 00:07:03.550

Taylor: And I've, I've had lots of medical issues over my life. So it was very comfortable (gestures with hands to illustrate point) to me, to be always be in (laughs) hospital and talking to medical professionals. So,

55

00:07:03.874 --> 00:07:10.245

Taylor: I I knew how (gestures with hands to illustrate point) to deal with that and what I've done in the past is just, like completely just (gestures with hands to illustrate point) I will rely on myself.

56

00:07:10.710 --> 00:07:12.940

Taylor: So throughout the pregnancy it was a …

57

00:07:12.970 --> 00:07:15.680

Taylor: that was the kind of the mode I went into.

58

00:07:16.129 --> 00:07:20.320

Taylor: The birth was fine. It was a planned C-section and it all went well.

59

00:07:20.697 --> 00:07:40.489

Taylor: The first kind of … she was born six weeks before the pandemic, like before Lockdown started. So the first (gestures with hands to illustrate point) six weeks I was just in a delirious state of hormones and whatever else. It was … but I did notice once we went into pandemic (gestures with hands to illustrate point) and I didn't have any support, I rea… that's when I really (gestures with hands to illustrate point) kind of

60

00:07:42.130 --> 00:07:57.340

Taylor: numbed out, is the way I did it. I just (touches forehead) I and I don't know (shrugs shoulders), maybe part of it, we all had to kind of do that, didn't we? Our worlds (gestures with hands to illustrate point) kind of shrank but but as a new mother, who was already kind of, my like mode (gestures with hands to illustrate point) was to just go, I will do it all and I will …

61

00:07:57.560 --> 00:08:05.636

Taylor: I will ignore how I feel (gestures with hands to illustrate point) or what my needs are and just switch off. But again, I can't (shakes head) remember la… large parts of it.

62

00:08:06.960 --> 00:08:13.689

Taylor: I, I watch videos to remember what what it was like (laughs) or what she was like.

63

00:08:14.137 --> 00:08:20.249

Taylor: And some… sometimes it’s quite upsetting cause I'm like I can't even … I don't know how I felt then or like what, (pauses)

64

00:08:22.410 --> 00:08:27.490

Taylor: you know, they look like happy times and I'm like I don't think I was. I think I was completely (waves hand in front of face) just…

Sarah: Mmm

65

00:08:27.700 --> 00:08:33.435

Taylor: …shut off. I did … the GP did put me on (pauses)

66

00:08:35.120 --> 00:08:48.090

Taylor: medication at the time cause they kind of felt I had a depression, postpartum depression, but I don't think it was that. I think I just completely shut off, so I on… I stayed on those for about six months and I did have some

67

00:08:48.230 --> 00:08:50.420

Taylor: CBT

68

00:08:51.200 --> 00:08:59.419

Taylor: therapy, but it … I dunno, it wa… it didn't really get to the (gestures with hands to illustrate point) the root of it. It was quite surface level, but you know it kind of got me through, I suppose, so…

69

00:08:59.420 --> 00:09:07.219

Sarah: Mmm, and was that experience … did it affect your experiences of depersonalisation and derealisation as well?

70

00:09:08.390 --> 00:09:09.450

Taylor: What the…?

71

00:09:09.680 --> 00:09:13.719

Sarah: Kind of that time, it sounds like you know, you were shut down a bit.

72

00:09:13.790 --> 00:09:15.529

Sarah: The … I mean the pandemic was a stressful…

73

00:09:15.530 --> 00:09:33.810

Taylor: (interrupting interviewer) It didn't … I didn't realise I was doing it. I just thought it was the pandemic. Everyone was struggling, and as a new mother, not knowing what I'm doing and having a not very supportive partner, I just thought it was, I kind of blamed like (gestures with hands to illustrate point) the situation if you like, rather than…

Sarah: (interrupting and speaking over Taylor) Yeah

Taylor: …the way I was reacting to it because I think…

74

00:09:34.360 --> 00:09:39.949

Taylor: it has been such a mode (gestures with hands to illustrate point) for me to like … it works. I get through things, if I operate (laughs) like that, like,

75

00:09:40.140 --> 00:09:47.419

Taylor: you know, everyone stays safe. My world (gestures with hands to illustrate point) doesn't come crashing down and I don't (touches hands to chest) have to deal with any of my feelings, like I just (laughs) like

76

00:09:47.500 --> 00:09:55.959

Taylor: power through. So I think I was just more kind of, well, everyone's okay, so you know, I'll just keep going kind of thing is what….

77

00:09:55.960 --> 00:09:56.460

Sarah: Yeah

78

00:09:56.460 --> 00:10:01.189

Taylor: But then it was, yeah, two years kind of after that that I realised, no, I'm not okay.

79

00:10:01.260 --> 00:10:02.609

Sarah: Right (nods head)

80

00:10:02.750 --> 00:10:07.359

Taylor: And … and, as she was getting older, I was like, I don't want her to

81

00:10:07.380 --> 00:10:11.270

Taylor: to kind of see how I'm behaving basically, and and

82

00:10:11.630 --> 00:10:18.709

Taylor: I want my relationship with her to be authentic and erm yeah. I need to deal with my own stuff in order to kind of

83

00:10:19.870 --> 00:10:20.770

Taylor: enable that.

84

00:10:21.370 --> 00:10:22.800

Sarah: Yeah, definitely.

85

00:10:23.520 --> 00:10:30.759

Sarah: And can you describe to me what it feels like to be depersonalised and derealised?

86

00:10:31.080 --> 00:10:34.150

Taylor: Yeah, so for me. I'll tell you about a particular event that …

87

00:10:34.160 --> 00:10:56.260

Taylor: it it was this time last year when I really … it clicked for me. I'm like, "oh, I'm doing it. It's happening right now," and it was … we were going to see Father Christmas (laughs) which I know sounds silly, but for me I have a thing around, if events are supposed to be really happy (gestures with hands to illustrate point), I I put too (emphasises the word too) much pressure and stress on being responsible for them being happy, like this has to go well, this has to, you know, I should enjoy this.

88

00:10:56.951 --> 00:11:18.370

Taylor: So on the way (gestures with hands to illustrate point) there, I noticed I was getting (holds hands to chest) just tense (clenches fists together and raises shoulders demonstrating being tense) in my whole body and my breath was getting shorter, so I could feel it (touches chest again) actually physically in my body. So I just started (gestures with hands to illustrate point) trying to talk to myself about like what (gestures with hands to illustrate point) will be will be. It doesn't matter if this is the best Christmas activity ever or not.

89

00:11:19.960 --> 00:11:25.459

Taylor: But throughout (gestures with hands to illustrate point) the day, cause we were there most of the day, it was like a whole experience thing.

90

00:11:25.815 --> 00:11:40.289

Taylor: I could just feel myself completely (waves hand across face to demonstrate zoning out) zoning out and not remembering what had happened, like, how had I got here, like we were at the other (gestures with hands to illustrate point) side of the park. I can't even remember how we got here. I can't remember, have I got my bag with me? Have I got my child with me? I can't remember like (gestures with hands to illustrate point)

91

00:11:40.983 --> 00:11:45.379

Taylor: what I've done, but I was with a friend, but I just remember laugh…

92

00:11:45.450 --> 00:11:52.270

Taylor: I was laughing and I was like, why am I … I don't even know why I'm laughing and she was obviously telling me a story or something and I just flipped (clicks fingers) into a …

93

00:11:52.530 --> 00:11:57.525

Taylor: it was like (gestures with hands to illustrate point) I was watching someone else, like just play my part.

94

00:11:58.980 --> 00:12:07.179

Taylor: And so I kept, that was the f… one of the first times I could like fee… like snap myself out of it for a moment and just realise what I was doing.

95

00:12:07.632 --> 00:12:13.989

Taylor: So I almost like shake (shakes body) and like try and like physically (raises shoulders) like wake myself (laughs) up, is what I try and do

96

00:12:14.865 --> 00:12:15.620

Taylor: and

97

00:12:15.710 --> 00:12:24.460

Taylor: try and tell (gestures with hands to illustrate point) myself, I want to be present, I want to … I want to experience this, whether it's good (gestures with hands to illustrate point) or bad. It's okay, kind of thing and try and reassure myself.

98

00:12:26.730 --> 00:12:34.400

Taylor: Which sometimes works but sometimes I just l… I try and let it flow (moves hand across body to demonstrating flowing) through me. Like, it's okay, like, okay, it's happening, like (shrugs shoulders).

99

00:12:34.930 --> 00:12:44.390

Taylor: No one else can tell. That's my main thing as well. I don't need to be embarrassed, like, no one else can probably see that that's (touches chest with hand) how I'm feeling because I'm still acting (makes quotation marks in the air with fingers) normally from

100

00:12:44.900 --> 00:12:52.950

Taylor: on the outside. And then I try and … cause quite often I feel really, really guilty afterwards that I didn't, I didn't (emphasises the word didn't) enjoy (gestures with hands to illustrate point) it and I wasted (gestures with hands to illustrate point) it, and

101

00:12:54.400 --> 00:13:00.569

Taylor: so I try and like (moves hand down in front of face) as I'm kind of … as the event is finishing, like as in we were leaving (gestures with hands to illustrate point) the Father Christmas thing.

102

00:13:00.850 --> 00:13:02.659

Taylor: Just try and say, like,

103

00:13:03.968 --> 00:13:11.281

Taylor: you know (gestures with hands to illustrate point), “it's not … it's not my fault and everyone else around me will of had a nice time,” and

104

00:13:12.000 --> 00:13:16.715

Taylor: yeah, just try and calm myself down. I take a lot of photos and videos

105

00:13:17.280 --> 00:13:21.579

Taylor: and that's because I'm trying to like cling on like, no (points with finger on hand), look, it was happy (laughs).

106

00:13:21.970 --> 00:13:35.509

Taylor: I don't necessarily always think that's a good or a bad idea cause I I do tend (gestures with hands to illustrate point) to get then quite focused into … I make sure I take lots of photos and videos and I don't know if that pulls (gestures with hands to illustrate point) me out of the moment being present as well. So that's one thing I'm kind of

107

00:13:36.560 --> 00:13:48.259

Taylor: working on as well cause I I may be using that as a bit of a crutch to kind of be like, it's okay that I've completely (gestures with hands to illustrate point) zoned out because, look, I took a photo (holds hand up in the air as if holding a phone) and therefore it did happen (smiles) and everything was okay, so yeah.

108

00:13:49.510 --> 00:13:52.200

Sarah: Yeah, thank you. And

109

00:13:52.540 --> 00:13:58.850

Sarah: you've mentioned a little bit about your childhood as well. Can you tell me about your childhood, please?

110

00:13:58.850 --> 00:14:05.384

Taylor: Yeah. So my my parents split up when I was two and it was quite … (pauses)

111

00:14:07.280 --> 00:14:21.349

Taylor: it was just traumatic, it was awful. There was violence, not (gestures with hands to illustrate point) directly at me, but as in like people busting (gestures with hands to illustrate point) doors down. My dad like taking my brother from our car, like kind of kidnapping him and…

112

00:14:21.380 --> 00:14:31.779

Taylor: So all my (gestures with hands to illustrate point) earliest memories are just really awful (laughs), kind of screaming or not feeling safe and not understanding (gestures with hands to illustrate point) why mummy and daddy are just like

113

00:14:31.880 --> 00:14:36.399

Taylor: hating each other and also throughout (gestures with hands to illustrate point) my childhood, they've then kind of

114

00:14:36.730 --> 00:14:51.330

Taylor: used me and my brother to attack each other in terms of like saying really awful things or cancelling plans with us to kind of get back at the other person. So it was just a lot of instability,

115

00:14:51.640 --> 00:14:53.339

Taylor: a lot of aggression.

116

00:14:54.042 --> 00:15:03.740

Taylor: Both of them have got … I wouldn't say their alcoholics but they've got problems with alcohol, so I didn't always feel just safe (shrugs shoulders) basically throughout.

117

00:15:04.506 --> 00:15:11.690

Taylor: They both have used me throughout childhood on into adult life, as well, as as a kind of a confidant (gestures with hands to illustrate point) and a kind of a …

118

00:15:12.263 --> 00:15:17.729

Taylor: a friend almost and shared too much with me and used me in a lot of ways. So

119

00:15:17.890 --> 00:15:25.379

Taylor: again, my trust in them and being my parents (gestures with hands to illustrate point) is not, is not what I needed and still not really what I need.

120

00:15:26.212 --> 00:15:30.010

Taylor: So, yeah, it's just, I don't have,

121

00:15:31.140 --> 00:15:42.000

Taylor: I suppose I'm just disconnected from both (gestures with hands to illustrate point) of the people that were supposed to be looking after me. I've had to rely on myself and I've just not as a child I just didn't understand why it was so

122

00:15:42.610 --> 00:15:49.716

Taylor: aggressive and not safe and so a lot of it, I've kind of been taking out on myself and like abuse my own body, I suppose.

123

00:15:50.890 --> 00:15:58.519

Taylor: And it's only kind (gestures with hands to illustrate point) of now, like 30 years later (laughs), I'm kind of working out like, okay, so what behaviours have I taken on

124

00:15:58.700 --> 00:16:09.689

Taylor: to cope with all of that? And and and and should I deal with how that's felt and how it's kind of shaped me as a person rather than continuing (gestures with hands to illustrate point) behaviours just to cope I suppose?

125

00:16:10.730 --> 00:16:11.400

Taylor: So, yeah.

126

00:16:11.960 --> 00:16:12.720

Sarah: Mmm

127

00:16:13.050 --> 00:16:17.660

Sarah: Were you living between your mum and your dad's house?...

Taylor: Yeah, yeah

128

00:16:17.660 --> 00:16:19.639

Sarah: What did that look like?

129

00:16:20.190 --> 00:16:35.500

Taylor: So we'd spend every other weekend with my dad and the rest of the time I'd live with my mum. My dad would travel for work quite a lot, so it'd be sometimes say summer holidays, sometimes we wouldn't see him very much or sometimes we'd have a solid 2 weeks with him. So again,

130

00:16:35.980 --> 00:16:46.380

Taylor: it was (gestures with hands to illustrate point) a lot of toing (gestures with hands to illustrate point) and froing and also the way they both ran their homes was completely different. So my dad was very strict, very clean,

131

00:16:46.770 --> 00:16:51.180

Taylor: children were the kind of there to entertain is the way I'd (laughs) put it

132

00:16:52.160 --> 00:16:58.979

Taylor: and to fit into his (gestures with hands to illustrate point) life. Whereas my mum was a bit more … well just laid back, chaotic and

133

00:17:00.007 --> 00:17:07.172

Taylor: like to spend money and and show her love through gifts. So it was kind of like very (gestures with hands to illustrate point) different

134

00:17:08.160 --> 00:17:10.179

Taylor: situations to be in as well.

135

00:17:13.430 --> 00:17:15.910

Sarah: Mmm, mmm, mmm, and did they have partners at all when you were growing up?

136

00:17:15.910 --> 00:17:23.870

Taylor: Yeah, so my dad (gestures with hands to illustrate point) left my mum for my stepmother. They got married, I think, when I was about 5.

137

00:17:24.359 --> 00:17:28.819

Taylor: And she in one (gestures with hands to illustrate point) hand, she was very loving

138

00:17:29.233 --> 00:17:32.236

Taylor: but in another heart … another way kind of …

139

00:17:33.940 --> 00:17:38.060

Taylor: she resented us and she was very

140

00:17:38.100 --> 00:17:52.729

Taylor: cold in a lot of ways and cruel. She's a very petite lady, and I (holds hand on chest) am not, so she was very cruel throughout my childhood in terms of like putting me on diets, telling me I was fat, telling me I wasn't worth,

141

00:17:52.960 --> 00:17:55.270

Taylor: you know, nice clothes cause I was too fat.

142

00:17:56.315 --> 00:18:02.820

Taylor: But in another way, she (laughs) … I don't know, she was really kind to us as (laughs) well. So it was a bit kind of

143

00:18:03.060 --> 00:18:09.430

Taylor: confusing. My mum got with my stepdad when I was 11.

144

00:18:10.452 --> 00:18:21.100

Taylor: He was married to someone else at the time. So there was a lot of arguments, like his ex-wife came over to our hou… You know, there was like more like violent incidents, I suppose.

145

00:18:22.560 --> 00:18:26.160

Taylor: So yeah, it it kind of added to the (laughs)

146

00:18:26.690 --> 00:18:31.559

Taylor: not feeling (laughs) very safe … (interrupts self) when I say all this, I'm like, no wonder (empahsises the word wonder) I've got issues (smiles) like (laughs) …

147

00:18:32.450 --> 00:18:42.919

Taylor: anyway. But again, he's very loving, they're still together but just how it all happened, and he's got (gestures with hands to illustrate point) … he's got two children and he keeps his l…

148

00:18:42.950 --> 00:18:47.610

Taylor: He's got two (gestures with hands to illustrate point) lives basically and so there's always that kind of like … it doesn't feel …

149

00:18:50.080 --> 00:18:57.129

Taylor: I don… I feel sorry for him that that my mum's kind of made him do that … have (gestures with hands to illustrate point) two separate lives and so I also feel,

150

00:18:57.470 --> 00:19:00.349

Taylor: you know, that's … it's just not nice basically (laughs) to be

151

00:19:00.370 --> 00:19:05.459

Taylor: feeling like that as well. So just instability in that as well, yeah.

152

00:19:05.970 --> 00:19:09.579

Sarah: Mmm, and you mentioned kind of violent incidents.

153

00:19:09.580 --> 00:19:10.240

Taylor: Yeah.

154

00:19:10.390 --> 00:19:13.269

Sarah: Can you describe a little bit about what happened?

155

00:19:13.470 --> 00:19:27.789

Taylor: So there was a couple that are really strong, where one of them was … I think it was obvious. I mean, I was like 12, so I don't fully know what happened, but I think it's obviously (gestures with hands to illustrate point) his ex-wife found out that he was moving in with my mum, like moving in with us

156

00:19:28.050 --> 00:19:40.679

Taylor: and she came over to our house and got hold of my mum by the throat and like pinned (gestures with hands to illustrate point) her against our … on our driveway and I … it was summer, I was playing outside with all my friends, so that all my friends were there to see this.

157

00:19:40.940 --> 00:19:47.640

Taylor: and I was obviously freaking (gestures with hands to illustrate point) out, trying (gestures with hands to illustrate point) to get her off my mum, not knowing what was happening

158

00:19:47.810 --> 00:19:55.950

Taylor: and I don't think I got hurt but I know there was like pushing and stuff like that. It was scary. So that was a particular incident and then …

159

00:19:58.720 --> 00:20:02.170

Taylor: I can't remember the other one, but yeah (gestures with hands to illustrate point), just things like that but…

Sarah: Yeah…

160

00:20:03.630 --> 00:20:04.830

Taylor: Although

161

00:20:04.830 --> 00:20:25.199

Taylor: it kind of felt familiar (laughs) to me, cause like my dad had done similar things to my mum when I was younger. So again at the time … that's the thing, like events like that felt normal and th… that's not normal and no one taught … like my parents … my mum did not talk to me about these things to check, are you okay or like, try to explain what had happened or anything.

162

00:20:25.250 --> 00:20:27.999

Taylor: It was just normal and and …

163

00:20:28.330 --> 00:20:43.570

Taylor: or or she'd more just get angry about it, and I was like … I a… always just remember feeling like, what about me? (waves hand in the air) Like you've not asked if … No one asked if I was okay or like saw that there was a small (waves hand in the air) hum… Sorry I'm gonna cry (becomes tearful and wipes eyes with hands) but there was a small person there, like it's not …

164

00:20:44.240 --> 00:20:48.180

Taylor: you you didn't look after me. You just looked after yourself or just…

165

00:20:48.410 --> 00:20:58.459

Taylor: I don't know. Part of me doesn't blame her cause she … you know she was in it as well. It was obviously hurtful and not good for her so I think she was just looking after herself in a lot of ways and (shrugs shoulders) I get it.

166

00:20:58.730 --> 00:21:00.549

Taylor: So yeah.

167

00:21:02.080 --> 00:21:02.830

Sarah: Yeah.

168

00:21:02.980 --> 00:21:06.230

Sarah: Yeah. Were you ever directly

169

00:21:07.330 --> 00:21:13.410

Sarah: the, I don't wanna use the word victim, but kind of…

Taylor: (interrupting interviewer) Yeah

Sarah: …did you ever experience it directly towards you?

170

00:21:13.710 --> 00:21:22.769

Taylor: Not not actua… I don’t know. I got … like my stepdad did a few things to me like push (gestures with hands to illustrate point) me up against walls and stuff like that but never like properly hit (gestures with hands to illustrate point).

171

00:21:22.850 --> 00:21:26.739

Taylor: But I … it was abusive and there was verbal abuse for sure.

172

00:21:27.220 --> 00:21:34.379

Taylor: Like, if I look back on it, if anyone treated my daughter the way that I was treated, I would call that abuse

173

00:21:34.780 --> 00:21:42.189

Taylor: but not full on like hitting (gestures with hands to illustrate point) or more just shoving and just a lot of shouting.

174

00:21:42.710 --> 00:21:46.870

Taylor: I mean … and my mum used to like smack (gestures with hands to illustrate point) us as well like when we were children as …

175

00:21:47.080 --> 00:21:55.262

Taylor: I don't know it was the eighties (laughs). I guess that's what they (all spoken laughing) did but but I (touches chest with hand) I remember a lot of those like r… really,

176

00:21:56.400 --> 00:22:00.879

Taylor: properly being scared and hurt and not really understanding why, why you're hitting me (laughs) basically,

177

00:22:01.320 --> 00:22:02.800

Taylor: that's not nice.

178

00:22:03.460 --> 00:22:04.400

Taylor: So yeah.

179

00:22:05.190 --> 00:22:05.615

Sarah: Yeah.

180

00:22:06.230 --> 00:22:11.249

Sarah: What about your relationship with your siblings? What was that like? … Have you got one or more than one?

181

00:22:11.250 --> 00:22:28.230

Taylor: I've got one (gestures with hands to illustrate point) full brother and then two … they're all (gestures with hands to illustrate point) a lot older than me. Two half-sisters, a stepbrother and stepsister and then two stepbrothers from my stepdad that I don't don’t know. So yeah and I'm (gestures with hands to illustrate point) the youngest of pretty much of all of that. So to me again, it was kind of normal that you'd have (gestures with hands to illustrate point)

182

00:22:28.750 --> 00:22:34.800

Taylor: lots of separate siblings but my brother is the one that I like properly (gestures with hands to illustrate point) like grew up with. If you,

183

00:22:34.810 --> 00:22:40.029

Taylor: if you like. My relationship now, with him, I'm quite distant. His… (long pause)

184

00:22:41.710 --> 00:22:54.850

Taylor: I mean with … I don't know. We we see each other, but I emotionally (gestures with hands to illustrate point) keep him quite distant cause his experience … he's always trying (gestures with hands to illustrate point) to find the answer. So he says things like, “I think Dad might be autistic and that's why he did what he did” or

185

00:22:55.243 --> 00:23:08.079

Taylor: “I think mum had trauma from her childhood so that's why she (emphasises the word she) did what she did” and I'm I’m not about … I (places hand on chest) don't, I don't know why they did the things they did. I don't (shakes head) want explanations. I don't need that. I need (taps hand on chest) to work out for me.

186

00:23:08.508 --> 00:23:15.609

Taylor: I don't … it won't solve it for me if my dad is autistic (laughs). Like, you know, the event still happened, kind of thing.

187

00:23:15.640 --> 00:23:24.970

Taylor: So I struggle to connect with him because he's always trying to find the answer, whereas I'm more like trying (gestures with hands to illustrate point) to be more present and deal with the now and who I am now kind of thing.

188

00:23:25.598 --> 00:23:37.409

Taylor: I'm quite close (gestures with hands to illustrate point) to my sisters but they both live in America so I don't … when we do see each other, we're a good support system for each other, but we don't (shakes head) see each other more than like once a year really, so, yeah.

189

00:23:38.540 --> 00:23:41.720

Sarah: And did you have grandparents growing up?

190

00:23:41.720 --> 00:23:49.370

Taylor: Yeah, so yeah, both sets. My dad's side, we only really saw in like school holidays.

191

00:23:49.710 --> 00:23:56.890

Taylor: There was, I don't know, stuff going on between them as well but I don't (shakes head) think my granddad was a very nice person, but I don't really have any

192

00:23:57.070 --> 00:23:59.100

Taylor: particular bad memories.

193

00:23:59.720 --> 00:24:01.859

Taylor: And then, on my mum's (gestures with hands to illustrate point) side,

194

00:24:02.341 --> 00:24:10.110

Taylor: my nanny and grandpa (lists on fingers). My grandpa was not (emphasises the word not) a nice person (laughs). Very strict, very hierarchical, very misogynistic

195

00:24:10.740 --> 00:24:14.748

Taylor: but my mum idolised him.

196

00:24:15.410 --> 00:24:25.159

Taylor: And so there was always that again, that juxtaposition (gestures with hands to illustrate point) of like (gestures with hands to illustrate point) you idolise, I'm supposed to adore this person but I don't think he's very nice, and I'm actually quite scared of him.

197

00:24:25.690 --> 00:24:32.656

Taylor: And, yeah, my nanny was kind of … she was lovely and caring, warm

198

00:24:33.390 --> 00:24:37.310

Taylor: but again quite chaotic in her nature. So,

199

00:24:38.020 --> 00:24:48.060

Taylor: she ended up getting Alzheimer's as well, but that ki… it … we didn't realise for quite a while cause that was kind of her nature a bit as well, to be disordered (gestures with hands to illustrate point), and lots of thoughts and lots of conversation and… (tails off)

200

00:24:48.690 --> 00:24:55.070

Taylor: So again, I didn't feel particularly kind of bonded to her cause she was, she was lovely (emphasises the word lovely), but a bit chaotic (laughs).

201

00:24:57.050 --> 00:25:03.150

Sarah: Yeah, yeah. What about school? What was school like for you?

202

00:25:03.890 --> 00:25:06.300

Taylor: So I had a good set of friends

203

00:25:06.540 --> 00:25:09.739

Taylor: that we kind of (gestures with hands to illustrate point) moved up all the way through school.

204

00:25:10.120 --> 00:25:19.100

Taylor: I was bullied a little bit when I was about 11 or 12 but not not terribly so.

205

00:25:20.100 --> 00:25:24.469

Taylor: I don't have particularly like horrific memories or anything.

206

00:25:24.700 --> 00:25:38.840

Taylor: When I was 15, my supposed best friend at the time basically started bullying me and disowned me and got me kicked out of our friendship group and that still hurts cause they're all still friends and I still see them (gestures with hands to illustrate point) on Instagram or whatever meeting up

207

00:25:39.350 --> 00:25:42.369

Taylor: and I was the (gestures with hands to illustrate point) only one that was kind of kicked out.

208

00:25:43.021 --> 00:25:53.639

Taylor: So that hurt and that that that age as well. It was … it was awful. Like that was the time I needed and that's when my dad (gestures with hands to illustrate point) was divorcing my stepmum at that time.

209

00:25:54.374 --> 00:25:57.286

Taylor: So I was not a good place.

210

00:25:58.700 --> 00:26:07.770

Taylor: But otherwise, I did enjoy school and I was good at school. I, you know, enjoyed lessons, and I did well, but it wasn't …

211

00:26:08.010 --> 00:26:13.129

Taylor: you know most (gestures with hands to illustrate point) of it, it was good. I had good set of friends, and then as I got into kind of teenage years it was (shakes head),

212

00:26:14.120 --> 00:26:16.420

Taylor: it was not good (laughs and speaks in different tone of voice), yeah.

213

00:26:17.607 --> 00:26:20.000

Sarah: Mmm, mmm, so things kind of deteriorated.

214

00:26:20.260 --> 00:26:29.340

Taylor: Yeah, and I still don't really understand why. I think it's cause a lot of them started having boyfriends and I just wasn't that interested and I didn't really understand like

215

00:26:29.950 --> 00:26:38.720

Taylor: the conversations they were having. Like some of them, were starting to have sex and I was like, I don't even think about that, like I just had that disconnect (gestures with hands to illustrate point). So I assume it's cause I was just different.

216

00:26:38.850 --> 00:26:41.999

Taylor: But, but the way she went about it,

217

00:26:42.831 --> 00:26:50.848

Taylor: it was painful, like she rea… she properly just bullied me out and and made me feel … again cause I'm not tiny (gestures with hands to illustrate point and laughs).

218

00:26:51.730 --> 00:26:56.490

Taylor: She made it a lot about my physical appearance but I think that's cause she knew that that's what …

219

00:26:56.640 --> 00:27:02.100

Taylor: that's my weak spot. Like she knew how to … to use that, I suppose.

220

00:27:02.960 --> 00:27:05.140

Sarah: Yeah, yeah, absolutely.

221

00:27:08.300 --> 00:27:13.559

Sarah: Did you experience kind of any mental health difficulties during your childhood?

222

00:27:14.520 --> 00:27:31.419

Taylor: I, so I had a therapist. I think I was about five. I remember going, he was called Bob and I just remember I used to go see Bob once a week (laughs) and we used to play games and play with like certain (gestures with hands to illustrate point) dolls and things like that or used to… I remember he used to make me draw pictures of my family and my friends and

223

00:27:31.450 --> 00:27:34.070

Taylor: things like that, so I've got quite vivid memories.

224

00:27:35.700 --> 00:27:41.539

Taylor: I don't … I've never asked like, "what triggered like me going there? Did something happen?"

225

00:27:42.367 --> 00:27:45.002

Taylor: But I do remember going

226

00:27:45.590 --> 00:27:49.659

Taylor: and then again, when I was around 15, I …

227

00:27:50.090 --> 00:27:52.399

Taylor: yeah, I really suffered then.

228

00:27:52.630 --> 00:27:58.400

Taylor: I tried to go to my GP but at that time, I don't know, it just wasn't talked about like depression or feeling …

229

00:27:58.660 --> 00:28:03.559

Taylor: I wasn't suicidal, but I was very down, so I wrote to my sisters

230

00:28:03.770 --> 00:28:09.106

Taylor: because we didn't have phones (laughs) back then, mobile phones, and tha… I basically went and spent

231

00:28:09.460 --> 00:28:12.817

Taylor: two or three months with them living in America (pauses)

232

00:28:14.850 --> 00:28:19.509

Taylor: to … (interrupts self) but again, I don't fully. I've kind of blocked (gestures with hands to illustrate point) it out. I don't really remember

233

00:28:19.730 --> 00:28:24.040

Taylor: how that ha… I remember writing to them and I remember obviously being there…

234

00:28:24.040 --> 00:28:25.320

Sarah: (interrupting Taylor) How old were you then?

235

00:28:25.320 --> 00:28:26.230

Taylor: 15.

236

00:28:26.230 --> 00:28:31.460

Sarah: Okay (nods head). So around the same time as that bullying and being pushed…

Taylor: (interrupting and speaking over interviewer) yeah

Sarah: …out of that friendship group as well.

237

00:28:31.460 --> 00:28:32.940

Taylor: Yeah, exactly.

238

00:28:35.820 --> 00:28:38.673

Taylor: Yeah, so I kind of did that but then …

239

00:28:39.330 --> 00:28:44.440

Taylor: I mean looking back on it, I … I should (shrugs shoulders) have been in therapy and I might have even needed medication but

240

00:28:46.390 --> 00:28:53.200

Taylor: my mum just got quite angry at me. Like I remember like slapping (gestures slapping with hand) me. In fact, you’ve just reminded (gestures with hands to illustrate point) me because I (rubs eyes with hand) (pauses),

241

00:28:54.790 --> 00:29:00.315

Taylor: oh I can't even remember what happened but I was basically like blamed for being down like like

242

00:29:01.760 --> 00:29:07.850

Taylor: she didn't want to deal with it basically. So I think part of it was like, “go (gestures with hands to illustrate point) go live with your sisters for a bit. I don't really wanna deal with this.”

243

00:29:10.670 --> 00:29:17.419

Taylor: But … and then … I don't know, at university I … again I had what I'd call counselling. It wasn't very good.

244

00:29:17.789 --> 00:29:24.500

Taylor: It, it was a … just a chance to talk kind of thing but again I should of gone to my GP and I didn't.

245

00:29:24.880 --> 00:29:35.240

Taylor: So it's only until recently that I've gone, well … that you know (gestures with hands to illustrate point), I keep having not episodes but moments when I'm like I … this isn't right (shakes head), like, I'm not feeling good and I'm not happy and (pauses)

246

00:29:36.187 --> 00:29:45.960

Taylor: yeah, it's kind of since having my daughter, I've been like you better do something about it cause, you know, what if you wait another 10 years and then the impact it's gonna have on her as well, is not … it's not great, so yeah.

247

00:29:48.260 --> 00:29:49.040

Sarah: Mmm, mmm.

248

00:29:51.330 --> 00:29:52.070

Sarah: Okay.

249

00:29:52.690 --> 00:29:57.271

Sarah: And moving on a little bit, I wonder about

250

00:29:58.030 --> 00:30:02.829

Sarah: kind of your sense of self throughout all of these experiences. Do you feel like

251

00:30:03.000 --> 00:30:06.689

Sarah: you've got a clear idea of like who you are and your identity?

252

00:30:06.690 --> 00:30:07.320

Taylor: No (shakes head)

253

00:30:07.520 --> 00:30:15.839

Taylor: No, and that's … th … this will make me (points to eyes) cry. This is what I'm in therapy for still, kind of like. I don't know who I am or what makes me happy, or (tearful and rubs eye with hand)… (pauses)

254

00:30:17.700 --> 00:30:28.242

Taylor: Yeah, cause a lot of it, I thought I just hated myself and it's kind of like, I don't think I do hate myself. I think I just don't know who I am, cause I've never really been allowed to (very tearful and waves hands in front of eyes), sorry (laughs)

255

00:30:28.640 --> 00:30:30.009

Sarah: It’s okay. Do you want to pause?

256

00:30:30.996 --> 00:30:31.323

Taylor: I’m okay (sniffs).

257

00:30:34.220 --> 00:30:41.999

Taylor: Yeah, I've just kind of had (gestures with hands to illustrate point) a mode of like operating. I've just operated and whatever's happened to me (wipes eyes), I've just kind of carried on so…

258

00:30:42.210 --> 00:30:44.250

Taylor: But I don't (shakes head) want to live like that anymore (wipes eyes),

259

00:30:45.050 --> 00:30:45.830

Taylor: (sniffs) so yeah.

260

00:30:46.360 --> 00:30:47.360

Sarah: Mmm, mmm.

261

00:30:49.240 --> 00:30:57.250

Sarah: How do you feel like that sense of self was affected by kind of those early life experiences?

262

00:30:59.220 --> 00:31:05.720

Taylor: I think I was made to not feel good enough and I was made to feel like an object and I was used like an object. (pauses)

263

00:31:08.780 --> 00:31:16.330

Taylor: And I was never (pauses) emotionally supported. Like no one asked, “are you okay? How are you?”, so,

264

00:31:16.600 --> 00:31:22.570

Taylor: therefore, I didn't put any value in me or how do I feel, or what do I want? What do I need? (pauses)

265

00:31:26.020 --> 00:31:34.199

Taylor: And yeah (gestures with hands to illustrate point), I think it completely channelled me into finding a way to survive just to cope rather than to explore who am I and

266

00:31:35.560 --> 00:31:38.810

Taylor: yeah (pauses) what what do I want? What do I need? Yeah…

267

00:31:39.880 --> 00:31:40.540

Sarah: Mmm,

268

00:31:41.150 --> 00:31:48.240

Sarah: and do you feel like that sense of self has also been affected by depersonalisation and derealisation?

269

00:31:49.630 --> 00:31:51.174

Taylor: I thin… I think …

270

00:31:52.990 --> 00:31:58.479

Taylor: I think it's been really useful. It's been a place for me to go… it's where I feel safe when I just cut off.

271

00:31:58.820 --> 00:32:08.410

Taylor: It's … it's allowed me to continue not to know who I am and that's that's what I'm dealing with at the moment, trying not to use it in some ways when I feel it happening.

272

00:32:09.920 --> 00:32:15.930

Taylor: Just awareness of that takes you kind of further away of feeling (gestures with hands to illustrate point) and that's what…

273

00:32:16.040 --> 00:32:21.190

Taylor: kind of looping (gestures with hands to illustrate point) that back to, but I want to feel, and I want to know who I am and

274

00:32:21.200 --> 00:32:22.970

Taylor: experience things.

275

00:32:23.070 --> 00:32:31.457

Taylor: But that's scary cause I've not … I don't know how to do that. I don't know how to do (gestures with hands to illustrate point) it, like big feelings, I suppose.

276

00:32:33.370 --> 00:32:38.929

Taylor: So yeah, DPDR has kind of been like my safe place and what I know and how I know.

277

00:32:40.950 --> 00:32:42.835

Taylor: Yeah, it feels secure I suppose (sniffs).

278

00:32:43.667 --> 00:32:49.810

Sarah: Mmm, mmm. Like the image that I'm getting, I feel like that you're describing, is DPDR as a bit of a shield…

279

00:32:49.810 --> 00:32:50.360

Taylor: Yeah (nods head)

280

00:32:50.570 --> 00:32:52.530

Sarah: …to everything and

281

00:32:52.630 --> 00:32:57.559

Sarah: means that you don't have to learn who you are...

Taylor: (interrupting interviewer) Yeah

Sarah: …and I wonder if there's a worry of almost …

282

00:32:58.140 --> 00:33:04.989

Sarah: not liking po… worrying about not liking who you are or finding that out and it not being

283

00:33:05.170 --> 00:33:06.580

Sarah: a good feeling.

284

00:33:07.020 --> 00:33:12.949

Taylor: Yeah, or it's just a a … generally just a fear of like…

285

00:33:15.050 --> 00:33:18.750

Taylor: I don't know (laughs) and it's safer to not know in a lot of ways.

286

00:33:18.750 --> 00:33:19.570

Sarah: Mmm, mmm (nods head)

287

00:33:19.750 --> 00:33:22.439

Taylor: Like the fear of the unknown.

288

00:33:23.580 --> 00:33:28.180

Sarah: Yeah, yeah, it's better to just leave that box closed almost…

289

00:33:28.530 --> 00:33:33.607

Taylor: (interrupting and speaking over interviewer) Yeah, but then then I come back to yeah, but how's this going (laughs)? Like

290

00:33:34.100 --> 00:33:36.749

Taylor: I'm, I'm not happy…

291

00:33:36.750 --> 00:33:37.470

Sarah: No…

Taylor: …and

Sarah: …no

292

00:33:37.850 --> 00:33:40.410

Taylor: I've now got a child and I don't want …

293

00:33:40.910 --> 00:33:45.460

Taylor: like that matters more to me that I'm an authentic (touches chest with hand) full person for her…

294

00:33:47.090 --> 00:33:47.763

Taylor: …so yeah.

295

00:33:48.640 --> 00:33:56.209

Sarah: Kind of leads me to think about, how do you cope with experiencing depersonalisation and derealisation?

296

00:33:58.090 --> 00:33:58.710

Taylor: Now?

297

00:33:58.710 --> 00:33:59.350

Sarah: Yeah.

298

00:33:59.370 --> 00:34:01.000

Taylor: It happened… (pauses)

299

00:34:03.630 --> 00:34:05.420

Taylor: I was doing it a bit last week.

300

00:34:05.890 --> 00:34:11.300

Taylor: I try to … I try to let it (gestures with hands to illustrate point) wash over me and not give it too much attention (long pause).

301

00:34:14.679 --> 00:34:27.710

Taylor: And try and … I'm try… I've got a lot more awareness now of what … why is it happening and say just kind of checking, w… is it cause I'm stressed (lists options on fingers), is it cause an event's happening? Just trying to notice (gestures with hands to illustrate point) the pattern of it, like when is it happening to me?

302

00:34:28.030 --> 00:34:31.269

Taylor: And then trying to check in with myself,

303

00:34:32.000 --> 00:34:35.680

Taylor: like, is it still happening (gestures with hands to illustrate point) or is it over now (laughs), kind of things.

304

00:34:37.219 --> 00:34:40.565

Taylor: Try not to feel guilty cause that's my main thing.

305

00:34:41.060 --> 00:34:47.169

Taylor: So when it does happen, it's ok… it's okay and it's getting less and less.

306

00:34:48.085 --> 00:34:54.089

Taylor: So I just try and tell (gestures with hands to illustrate point) myself kind of like, you know, okay, it's happening right now, but it… y…

307

00:34:54.540 --> 00:34:58.720

Taylor: at the moment it feels like it will end whereas before it was just a constant (gestures with hands to illustrate point)

308

00:34:58.880 --> 00:35:04.500

Taylor: all for long periods of time. So trying to just be like compassionate with myself,

309

00:35:04.980 --> 00:35:08.299

Taylor: recognise I'm doing it and l… like an awareness of,

310

00:35:08.770 --> 00:35:14.970

Taylor: are there particular like situations where it's more prevalent to to just …

311

00:35:15.880 --> 00:35:21.030

Taylor: not necessarily to change any behaviours but just to have an awareness of it, what it is. Yeah (can’t make out words)

312

00:35:23.010 --> 00:35:24.110

Sarah: Thank you.

313

00:35:24.360 --> 00:35:31.020

Sarah: And now, sort of moving on to think a little bit about your diagnosis.

314

00:35:32.840 --> 00:35:40.889

Sarah: You've sort of talked a little bit about kind of being in therapy. What led you to going to therapy then?

315

00:35:41.360 --> 00:35:47.070

Taylor: So it was prob … it was kind of problems in my marriage and my husband blamed a lot of kind of (pauses)

316

00:35:48.590 --> 00:35:55.880

Taylor: our problems in our marriage about me not looking after myself physically and mentally. So

317

00:35:56.480 --> 00:36:02.240

Taylor: it was that that drove me to it. So it wasn't like … I was really sad and really not in a good

318

00:36:02.530 --> 00:36:04.499

Taylor: state health wise

319

00:36:05.050 --> 00:36:16.499

Taylor: but that wasn't bad enough (laughs) for me to do anything about … it was kind of him saying, “you need to go sort yourself out” kind of thing, so that's how it started. I have since realised like, even if

320

00:36:16.750 --> 00:36:19.630

Taylor: me sorting myself (makes quotation marks in the air with fingers) out kind of thing,

321

00:36:20.098 --> 00:36:22.431

Taylor: our marriage (gestures with hands to illustrate point) was not good and,

322

00:36:23.960 --> 00:36:27.210

Taylor: so yeah, we are now separating or have separated.

323

00:36:27.602 --> 00:36:29.840

Taylor: But yeah, that's how it started.

324

00:36:31.320 --> 00:36:34.280

Sarah: I'm just coming back to like the marriage not being good.

325

00:36:34.420 --> 00:36:35.010

Taylor: Yeah.

326

00:36:35.890 --> 00:36:43.370

Sarah: Wa… was that kind of similar to what you'd seen in the relationship with your parents, or…?

Taylor: (interrupting interviewer) Yeah

Sarah: Yeah

327

00:36:43.590 --> 00:36:55.669

Taylor: Completely (smiles and laughs)! I basically married my mother (laughs) (can't make out some of the words) to put it. So again, he's very detached (gestures with hands to illustrate point). He's very kind of absorbed in his own world. He's got ADHD and depression

328

00:36:56.411 --> 00:37:03.840

Taylor: and so he quite often can't give me the support emotionally that I need. He's not (shakes head) … it's not stable,

329

00:37:05.520 --> 00:37:19.380

Taylor: and it's been like that from the beginning. So yeah, kind of exploring with my therapist, like the reason why we kind of got together and why it worked and why I was happy is cause it was so familiar to me. Like, yeah, I can do this. I know exactly how to be in a relationship with someone like that.

330

00:37:19.970 --> 00:37:22.190

Taylor: So yeah (laughs).

331

00:37:23.846 --> 00:37:28.210

Sarah: Was there any like violence or anything in that relationship?

332

00:37:28.210 --> 00:37:31.069

Taylor: No, no, I mean he's quite …

333

00:37:31.390 --> 00:37:40.400

Taylor: he's manipulative and he's erm verbally abusive sometimes, (pauses) but no, not physical (shakes head), no.

334

00:37:40.640 --> 00:37:42.010

Sarah: Okay, yeah.

335

00:37:42.590 --> 00:37:48.099

Sarah: And, so you went to the therapist cause things

336

00:37:48.180 --> 00:37:55.244

Sarah: weren't really working well and you kind of needed to take better physical and mental care of yourself.

337

00:37:55.730 --> 00:38:01.219

Sarah: How, how did you find the therapist? Did you go through your GP? Did you look for something privately? What happened?

338

00:38:01.440 --> 00:38:03.650

Taylor: No, cause I went through my GP,

339

00:38:04.144 --> 00:38:11.469

Taylor: just after my daughter was born and I got sent straight to (claps hands together) CBT and I was just like I don't,

340

00:38:11.550 --> 00:38:23.520

Taylor: I know that's not what I need, it's something else. So I d… I went privately and just… I did some research, cause my main thing, I use food (places hand on chest), like I binge eat (gestures with hands to illustrate point) and then starve myself.

341

00:38:24.241 --> 00:38:33.169

Taylor: So I was like, I want someone who understands that that kind of cycle of behaviour. Someone who understands trauma and kind of like childhood

342

00:38:33.530 --> 00:38:47.840

Taylor: issues. So I did quite a bit of research (gestures with hands to illustrate point) and then spoke to a few different therapists on the phone to see that … I want someone I can connect with cause I need to open up and part of the problem with the the person I spoke to when I did CBT is, I just didn't connect with them at all and (pauses)

343

00:38:48.758 --> 00:38:56.969

Taylor: I just wanted to find someone that I felt comfortable with, so I went that way. I did talk to my GP about it,

344

00:38:58.690 --> 00:39:08.499

Taylor: and they were kind of like, yeah, there's also like huge wai… I guess (laughs), just a bit dismissive, like this huge waiting list and if you can afford to then please go (gestures with hands to illustrate point) over there (laughs), so (shrugs shoulders) yeah.

345

00:39:08.640 --> 00:39:11.785

Taylor: Which again, I don't (gestures with hands to illustrate point) blame them for, the NHS, yeah.

346

00:39:12.390 --> 00:39:17.800

Taylor: It's fine. But, when I have since been back though, when

347

00:39:18.150 --> 00:39:24.589

Taylor: my therapist has kind of diagnosed me for things, I've kind of gone back to my GP, just to say, like, this is happening, what do you think kind of thing

348

00:39:25.530 --> 00:39:33.010

Taylor: and they have been quite just dismissive and like, “Well, if you're not really really bad then unfortunately, I don't really care”. (laughs)

349

00:39:33.520 --> 00:39:35.149

Taylor: Kind of the vibe I got.

350

00:39:35.350 --> 00:39:37.240

Sarah: Okay (nods head), yeah,

351

00:39:37.410 --> 00:39:38.240

Sarah: yeah.

352

00:39:38.450 --> 00:39:41.140

Sarah: Sooo youuuu …

353

00:39:41.490 --> 00:39:52.309

Sarah: actually going back slightly, the the CBT like thing, was … and you said you went to your GP and you kind of got sent to that. Was that within …

354

00:39:52.390 --> 00:40:06.850

Sarah: like was that a mental health service? Was that an…

Taylor: (interrupting and speaking over interviewer) Yeah

Sarah: …IAPT service? It was (nods head) it was…

Taylor: (interrupting and speaking over interviewer) Yeah

Sarah: …a mental health. Was it just like the adult mental health team…

Taylor: (interrupting and speaking over interviewer) Yeah

Sarah: …or was it? Yeah. So I'm just mindful of the fact you said it was when you're … around the time your daughter was born and I know there's like perinatal sort of teams as well.

355

00:40:06.850 --> 00:40:09.979

Taylor: No, it was IPATHS or something? (spoken in questioning tone) I don't know what it is (places hand over mouth).

356

00:40:10.140 --> 00:40:10.750

Taylor: Oh, no.

357

00:40:10.750 --> 00:40:14.910

Sarah: Dunno. There's so many different names out there and things (laughs) as well.

358

00:40:14.910 --> 00:40:19.380

Taylor: Yeah, but it was the mental health team…

Sarah: (interrupting Taylor) Okay

Taylor: …because it was Covid times, it was all done on the phone …

359

00:40:19.380 --> 00:40:20.110

Sarah: Right.

360

00:40:20.330 --> 00:40:22.880

Taylor …so it was really like hard to open up, when you've got (gestures with hands to illustrate point) (can't make out words)

361

00:40:22.880 --> 00:40:27.309

Sarah: (interrupting and speaking over Taylor) Yeah, so just on the phone, not not with like…

Taylor: (interrupting and speaking over interviewer) No…

Sarah: …video or anything.

362

00:40:27.310 --> 00:40:31.390

Taylor: no, it was kind o… it was near the start of the pandemic, so we hadn't sorted zoom out yet I suppose. (Taylor and interviewer laugh)

363

00:40:31.797 --> 00:40:34.240

Sarah: Everyone was still learning and…

Taylor (interrupting and speaking over interviewer) Yeah

Sarah: …panicking (Taylor laughs). Yeah…

Taylor: Yeah

364

00:40:35.090 --> 00:40:37.786

Sarah: Yes, remember those days well. (Taylor and interviewer laugh)

365

00:40:40.630 --> 00:40:56.910

Sarah: Okay, so then you found your therapist and and what is the the role of your therapist? Is she … I'm I'm assuming it's a she actually…

Taylor (interrupting and speaking over interviewer) Yeah it's a she

Sarah: … it might be a he. Is she, I don't know a psychologist? Is she a psychiatrist? What what's her background?

Taylor: Can look her up (interviewer laughs) (Taylor gets phone and starts searching)

366

00:41:01.930 --> 00:41:03.274

Sarah: Just being nosey now (laughs) (long pause for almost 30 seconds)

367

00:41:27.090 --> 00:41:28.430

Taylor: Psychologist.

368

00:41:28.740 --> 00:41:31.379

Sarah: Okay (nods head), she's a clinical psychologist?

369

00:41:31.380 --> 00:41:31.990

Taylor: Yeah…

Sarah: Okay

370

00:41:32.130 --> 00:41:34.200

Taylor: (interrupting and speaking over interviewer) …and then I think she report…

371

00:41:34.350 --> 00:41:37.930

Taylor: she has someone like overseeing (gestures with hands to illustrate point) her work (not sure the word work is what Taylor said) ... I think it's a psychiatrist. Is that different?

372

00:41:37.930 --> 00:41:39.270

Sarah: Right, right.

373

00:41:39.933 --> 00:41:43.179

Sarah: Yeah, psychiatrists and psychologists are slightly different.

374

00:41:43.180 --> 00:41:44.890

Taylor: Yeah, I think that's what she said.

375

00:41:44.890 --> 00:42:02.049

Sarah: Psychiatrists are moreee medical,…

Taylor: Yeah

Sarah: …so they're more likely to give diagnoses and…

Taylor: Yeah (nods head)

Sarah: …and like medication, things like that (Taylor nods head). Whereas psychologists are more about understanding the problem…

Taylor: Yeah

Sarah: …and then thinking about it from a more psychological point of view.

376

00:42:02.050 --> 00:42:06.009

Taylor: Yeah, cause I think when she was diagnosing me with that and also we did EMDR and she was…

377

00:42:06.010 --> 00:42:06.330

Sarah: (interrupting Taylor) Okay.

378

00:42:06.330 --> 00:42:09.100

Taylor: …going (gestures with hands to illustrate point) to them about whether that was the best.

379

00:42:09.100 --> 00:42:13.640

Sarah: Okay, okay, so did you ever meet with the psychiatrist that she?...

Taylor: (interrupting interviewer) No.

Sarah: No, no.

380

00:42:14.060 --> 00:42:15.900

Taylor: But she has kind of said sh…

381

00:42:16.690 --> 00:42:21.649

Taylor: she kind of goes back to him to reflect on stuff, I suppose, and get his advice and then she said, if if

382

00:42:21.850 --> 00:42:25.360

Taylor: she felt that she needed to then

383

00:42:25.520 --> 00:42:27.410

Taylor: I could access him basically but… (trails off)

384

00:42:27.410 --> 00:42:29.139

Sarah: Yeah, yeah.

385

00:42:29.280 --> 00:42:37.820

Sarah: So she's the one who mentioned to you about depersonalisation and derealisation. Had you ever heard of it before then?

386

00:42:37.820 --> 00:42:38.360

Taylor: No

387

00:42:39.380 --> 00:42:40.210

Sarah: Okay.

388

00:42:40.400 --> 00:42:43.849

Sarah: So it was something that was completely new to you.

389

00:42:44.200 --> 00:42:47.769

Taylor: Yeah, but we did quite a few different assessments, like different (shakes hand)

390

00:42:48.860 --> 00:43:00.639

Taylor: yeah, assessments and it was (laughs) … she was like, “no, you've definitely got this,” kind of thing. It was quite a light bulb, like, “oh, yeah”. So I don't know (gestures with hands to illustrate point), there was a list of like, I don't know 10 symptoms, and I had seven of them and

391

00:43:02.700 --> 00:43:13.029

Taylor: yeah. So she gave me quite a lot of reading and things like that to do as well, like different studies, or whatever else because that's what I like doing to like research, so

392

00:43:13.040 --> 00:43:16.809

Taylor: that was really helpful. That's helped me kind of understand

393

00:43:17.990 --> 00:43:19.760

Sarah: more about it, I suppose.

394

00:43:20.140 --> 00:43:25.130

Sarah: Mmm, mmm and then has that that diagnosis

395

00:43:25.140 --> 00:43:29.889

Sarah: gone on your record do you know or is it…

Taylor: (interrupting and speaking over interviewer) I don’t…

Sarah: …just something that's verbally being said to you?

396

00:43:30.040 --> 00:43:41.980

Taylor: It's v… (sighs) verbally been said and then I went and spoke to my GP because I'm like, “yeah, do I need to do something, or do (gestures with hands to illustrate point) they need to do some assessment or anything like that?” and that's when they were just like dismissive and like, well (shrugs shoulders) …

397

00:43:43.260 --> 00:43:47.810

Taylor: yeah. So I don't know if anything's ever been written down or if they're gonna do anything about it but …

398

00:43:48.090 --> 00:43:54.050

Taylor: I more care about like, well, how do I feel (places hand on chest) when I feel like what (gestures with hands to illustrate point) I'm doing with my therapist is helping me so like.

399

00:43:54.390 --> 00:43:55.780

Sarah: Yeah, (Taylor speaks but can’t make out words) yeah.

400

00:43:55.780 --> 00:44:01.229

Taylor: But I don't need it written down r… right now or I don't need (emphasises the word need) my GP to do anything…

Sarah: (interrupting and speaking over Taylor as phone rings) Sorry

Taylor: It's okay.

(interview paused for interviewer to deal with phone)

401

00:44:12.410 --> 00:44:13.830

Sarah: Sorry about that.

402

00:44:14.320 --> 00:44:14.990

Taylor: It’s okay.

(conversation removed as not relevant to interview)

417

00:44:38.090 --> 00:44:42.650

Sarah: So, sorry you're gonna have to jog my memory (laughs). What did?... What was just?

418

00:44:42.650 --> 00:44:46.650

Taylor: You were asking about like the diagnosis and like has it been written down or like just (can't make out word) that really?...

419

00:44:46.650 --> 00:45:00.800

Sarah: (interrupting and speaking over Taylor) Yeah, yeah, yeah. So you're saying that it it hasn't actually been written down, the … oh, yes (gestures with hands to illustrate point), the GP was quite dismissive and then you were talking a little bit about kind of … it was more important about the way that you're feeling and…

Taylor: (interrupting interviewer) Yeah

420

00:45:01.750 --> 00:45:09.480

Sarah: …dealing with that. What what did it feel like for someone to say, this is what I think is is happening for you?

421

00:45:09.920 --> 00:45:12.389

Taylor: A proper light bulb moment and a proper like,

422

00:45:12.740 --> 00:45:13.910

Taylor: “oh okay”,

423

00:45:13.950 --> 00:45:23.440

Taylor: Like, I've been diagnosed with lots (gestures with hands to illustrate point) of things (laughs) throughout my life, so again, it feels familiar, and I like that, cause then I can go research (lists on fingers) it and that means there's something I can do about it and it's not just a (gestures with hands to illustrate point),

424

00:45:24.108 --> 00:45:29.090

Taylor: a you know an unknown, so yeah, it felt good.

425

00:45:29.360 --> 00:45:37.109

Sarah: Mmm, mmm and you just said as well that you've been diagnosed with lots of things in your life. Can you tell me a bit about the different diagnoses you've received?

426

00:45:37.110 --> 00:45:40.030

Taylor: Yeah, so I've got polycystic (lists on fingers) ovary syndrome,

427

00:45:40.893 --> 00:45:48.950

Taylor: I've had cancer three times, all the same (gestures with hands to illustrate point) cancer like recurring, hyperthyroidism,

428

00:45:49.806 --> 00:45:55.700

Taylor: when I was pregnant I had gestational diabetes and then I was pre-diabetic (gestures with hands to illustrate point)

429

00:45:56.080 --> 00:46:01.379

Taylor: up until recently but I've lost some weight so that's gone now hopefully (says hopefully very quietly).

430

00:46:02.130 --> 00:46:03.070

Sarah: Wow

Taylor: So yeah

431

00:46:03.930 --> 00:46:14.239

Sarah: Wow, and and just picking up on like having cancer, which obviously is a is a huge thing as well. How old were you when when you got that diagnosis?

432

00:46:17.340 --> 00:46:24.919

Taylor: (closes eyes thinking and quietly talks to herself working it out) So I was max 27…

Sarah: (interrupting and speaking over Taylor) Okay

Taylor: when I was first diagnosed

433

00:46:25.520 --> 00:46:29.190

Taylor: …and then it recurred three times, (corrects self) another two times.

434

00:46:32.060 --> 00:46:34.210

Taylor: So the last one was 2017, yeah.

435

00:46:35.560 --> 00:46:44.579

Sarah: Okay, okay, and what about any kind of mental health diagnoses as well?

436

00:46:45.260 --> 00:46:55.290

Taylor: No, well no, other than, yeah, when I went to the GP after I had my daughter and she's like, “oh, maybe you've got post-partum depression”…

Sarah: (Interrupting and speaking over Taylor) Oh yes

Taylor: …but that was … I don't know, that was just off a composite, you know.

437

00:46:56.050 --> 00:46:58.289

Sarah: Yeah, sort of thrown out.

438

00:46:58.290 --> 00:47:00.399

Taylor: Yeah and I don't think it …

439

00:47:00.530 --> 00:47:02.929

Taylor: really … I don't know, maybe it was, but yeah.

440

00:47:03.680 --> 00:47:04.530

Sarah: Yeah.

441

00:47:05.210 --> 00:47:06.140

Sarah: Yeah.

442

00:47:06.390 --> 00:47:11.899

Sarah: So that's kind of the only time that you've really had a a different diagnosis.

443

00:47:12.130 --> 00:47:18.030

Sarah: Yeah …and … I'm just sorry. I've got a a list of questions and things to think about here…

444

00:47:18.030 --> 00:47:18.470

Taylor: (Interrupting and speaking over interviewer) No, don’t worry.

445

00:47:18.951 --> 00:47:21.358

Sarah: I'm just having a think. (long pause)

446

00:47:25.560 --> 00:47:26.870

Sarah: Sooo, (pauses again)

447

00:47:28.970 --> 00:47:40.949

Sarah: are there … I … do you feel like that is a good summary of of your story in terms of like getting that diagnosis or is there anything else kind of to add, I guess, to that story?

448

00:47:41.920 --> 00:47:48.950

Taylor: Well the only thing, cause right now I'm getting the help I need and I'm lucky… (interrupts self) oh, I (touches chest with hand) believe that's what I need, anyway, who knows? I should … maybe I should be doing other stuff.

449

00:47:49.200 --> 00:47:51.219

Taylor: But I'm lucky I can afford that,

450

00:47:51.390 --> 00:47:57.349

Taylor: and I do wonder say in the future (gestures with hands to illustrate point), if I if I needed more help and I couldn't afford it

451

00:47:57.570 --> 00:48:00.279

Taylor: and there's nothing like you say written down, (laughs)

452

00:48:00.700 --> 00:48:08.100

Taylor: I I do wonder what that journey would be like going going back to my GP or…

Sarah: Mmm

Taylor: so,

453

00:48:08.180 --> 00:48:25.789

Taylor: I kind of, I rest easy in in the kind of the the knowledge that hopefully I'll have enough money to go and access private stuff, but what if that isn't sufficient or … and also I I don't know what I should be accessing. I've found (gestures with hands to illustrate point) this particular therapist based on my own research but I'm not an expert.

454

00:48:25.880 --> 00:48:33.059

Taylor: So it is, I don't know slightly, not worrying, but I do consider like,

455

00:48:33.531 --> 00:48:39.070

Taylor: tha … that's why (stutters) I'm I'm fine right (gestures with hands to illustrate point) now and I feel like I'm getting what I need but who knows in the future? (gestures with hands to illustrate point)

456

00:48:39.560 --> 00:48:45.180

Sarah: Mmm, mmm (Taylor says something but can't make out words), and I think that kind of answers my my question about …

457

00:48:45.643 --> 00:48:58.400

Sarah: sorry I haven't asked it yet, but I was thinking about like what helped you to receive a diagnosis and it sounds a bit like, well, I I've had the money to go privately, that and I've get the support that I need.

458

00:48:58.400 --> 00:48:58.970

Taylor: Yeah.

459

00:48:59.551 --> 00:49:05.980

Sarah: And without that, then you might not of ever received that diagnosis…

Taylor (Interrupting and speaking over interviewer) No

Sarah: …I guess.

460

00:49:06.150 --> 00:49:07.310

Taylor: No, I…

Sarah: (Interrupting and speaking over Taylor) Yeah

461

00:49:07.310 --> 00:49:09.720

Taylor: …yeah, based on my experience with (gestures with hands to illustrate point)

462

00:49:10.640 --> 00:49:12.489

Taylor: cause I think … I think when I went

463

00:49:12.763 --> 00:49:28.650

Taylor: and got the CBT, that's that could have been a moment to do a proper assessment with me but at that time it was just no (gestures with hands to illustrate point), just go do CBT and then it … we got to the end of that course and the person doing therapy was kind of like, well, you seem in a better place, so I'm gonna discharge you, let me know. Go back to your GP if…

464

00:49:28.810 --> 00:49:29.416

Sarah: Mmm

465

00:49:29.720 --> 00:49:35.404

Taylor: …you're not. So I do, from my experience, yeah, believe that I don't think I would have easily (laughs)

466

00:49:36.030 --> 00:49:38.750

Taylor: got to where I am right now

467

00:49:39.000 --> 00:49:43.729

Taylor: without properly advocating for myself, and and basically yeah, pushing this.

468

00:49:43.730 --> 00:49:44.290

Sarah: Mmm

469

00:49:44.529 --> 00:49:51.480

Taylor: But it was k… I don't know, I always get the feeling when I have kind of mentioned things in the past, it's kind of like, yeah, you can go.

470

00:49:51.760 --> 00:49:56.349

Taylor: Do you want some medication basically? (Taylor and interviewer laugh) I'm like, I don't really …

471

00:49:56.890 --> 00:50:12.209

Taylor: that isn’t gonna help, that's gonna … and that's what happened when I took the antidepressants back then, it just numbed me (laughs) out even more and I was a bit … like looking back on that, I'm like, that's probably the worst thing (covers face with hands and then uncovers face) like … or not the worst thing, I don't know. It's just I don't think that's what I needed really.

472

00:50:12.470 --> 00:50:15.620

Sarah: I I think that's really interesting

473

00:50:15.690 --> 00:50:27.920

Sarah: because I think that's something that's coming up from other people as well…

Taylor: (interrupting and speaking over interviewer) Oh really? Okay.

Sarah: …is something to do with the medication, and it it not quite working with depersonalisation and derealisation, particularly if it is numbing.

474

00:50:27.920 --> 00:50:28.390

Taylor: Yeah.

475

00:50:28.757 --> 00:50:31.700

Sarah: Because that's kind of already what's happening, that's

476

00:50:31.900 --> 00:50:34.689

Sarah: part of what the experience is like.

477

00:50:34.690 --> 00:50:35.090

Taylor: Yeah.

478

00:50:35.525 --> 00:50:39.010

Sarah: So it probab… sometimes it increases those symptoms.

479

00:50:39.160 --> 00:50:44.989

Taylor: Yeah, I'm only just making that connection now, but quite possibly I think it probably did. I think,

480

00:50:45.190 --> 00:50:47.019

Taylor: it stopped me crying as much (laughs),

481

00:50:47.510 --> 00:50:49.219

Taylor: but maybe I needed to cry,

482

00:50:49.370 --> 00:50:51.636

Taylor: kind of thing (gestures with hands to illustrate point), so I don't know.

483

00:50:52.361 --> 00:50:58.379

Sarah: Yeah (laughs) it i… Yeah, it is difficult, isn't it? Cause sometimes we all need to cry and feel…

Taylor: (interrupting interviewer) Yeah

Sarah: …things

484

00:50:58.410 --> 00:51:05.980

Sarah: that's … that can be quite painful as well so … and we kind of develop these … th… this medication to stop us almost…

485

00:51:05.980 --> 00:51:06.720

Taylor: Yeah.

486

00:51:07.335 --> 00:51:07.950

Sarah: feeling.

487

00:51:08.520 --> 00:51:11.790

Sarah: Yeah, yeah. Is there anything that you think

488

00:51:12.260 --> 00:51:22.409

Sarah: helped you to receive … (interrupts self) no, hang on, I've asked that one. Is there anything that you think prevented you from receiving like an earlier diagnosis, for example, in the NHS?

489

00:51:23.250 --> 00:51:30.570

Taylor: Well I was 22 when I first got … (interrupts self) well no, when I was 15 even (gestures with hands to illustrate point), like, yeah, like, there's been moments where

490

00:51:31.000 --> 00:51:37.870

Taylor: if … if I'd had like a proper (emphasises the word proper) assessment and even just someone asking me like how was your childhood (laughs)? I think it would of …

491

00:51:38.350 --> 00:51:45.960

Taylor: but that never happened and if you think that's over three decades of opportunities I think that

492

00:51:46.160 --> 00:51:49.459

Taylor: if more interrogation was done.

Sarah: Mmm

493

00:51:50.200 --> 00:51:55.135

Taylor: Yeah, maybe. Oh, that's quite sad, though. That means I could have like (laughs and makes sad face), anyway (gestures with hands pushing away) yeah.

494

00:51:55.680 --> 00:52:02.419

Taylor: Yeah, there could have been…

Sarah: (interrupting and speaking over Taylor) It sounds…

Taylor: …more opportunities if proper assessment, I think, would have been done then (shrugs shoulders).

495

00:52:03.102 --> 00:52:05.149

Sarah: Mmm, mmm, it sounds like

496

00:52:05.160 --> 00:52:10.249

Sarah: you're feeling like, cause you've you've had contact with the healthcare system a couple of times around…

Taylor: (interrupting and speaking over interviewer) Yeah

497

00:52:10.310 --> 00:52:13.139

Sarah: …your mental or emotional state

498

00:52:13.270 --> 00:52:17.809

Sarah: and it sounds like those times were missed opportunities for you,

499

00:52:18.030 --> 00:52:18.570

Taylor: Yeah.

500

00:52:18.570 --> 00:52:21.259

Sarah: that could have been explored further.

501

00:52:21.350 --> 00:52:27.179

Sarah: When you were referred to the CBT side of things, did you have an assessment for that or…

Taylor: (interrupting and speaking over interviewer) No

Sarah: …what happen?

502

00:52:27.250 --> 00:52:28.550

Sarah: No, so it, was it a group?

503

00:52:28.720 --> 00:52:29.790

Taylor: Like forms…

504

00:52:29.790 --> 00:52:31.169

Sarah: (speaking over Taylor) No, it wasn't a group, it was just yeah…

505

00:52:31.450 --> 00:52:38.759

Taylor: Just me, just me and I … because … and they kind of said there was some (gestures with hands to illustrate point) forms like the scale of like one to 10 (gestures with hands to illustrate point) stuff, and…

506

00:52:38.760 --> 00:52:39.760

Sarah: Like questionnaires.

507

00:52:39.760 --> 00:52:40.930

Taylor: Yeah, exactly.

508

00:52:40.930 --> 00:52:41.640

Sarah: Yeah.

509

00:52:41.920 --> 00:52:44.540

Taylor: And

510

00:52:44.840 --> 00:52:58.759

Taylor: yeah (nods head), they were kind of like, because you're a new parent, your top of the list in terms of priority, so it was just straight (gestures with hands to illustrate point) in, like it was literally two weeks later, I got my first appointment. So I was impressed in terms of the speed, but yeah, I did feel a bit like, “I don't know if this is what I need.”

511

00:52:59.730 --> 00:53:07.429

Sarah: And and what happened like, how did the CBT work? Did they just go through tools? Or did they ask you about your experiences?

512

00:53:07.430 --> 00:53:12.459

Taylor: It was very focused on the present. It was kind of like what things are kind of …

513

00:53:13.200 --> 00:53:15.369

Taylor: I don't know, making you sad, or …

514

00:53:16.440 --> 00:53:24.539

Taylor: and then it it was very focused on solutions is how I felt, kind of like trying (gestures with hands to illustrate point) to do like the hot cross bun thing of like what, you know, what's …

515

00:53:24.830 --> 00:53:29.099

Taylor: you know. How does it physically feel? What's happening and what's your behaviour and and that…

516

00:53:29.270 --> 00:53:32.449

Taylor: and … but it was very in the moment (gestures with hands to illustrate point) and I was like, "well.

517

00:53:32.560 --> 00:53:40.180

Taylor: yeah, I'm sleep deprived, so I get really down," but I'm like, that's why it felt very surface (gestures with hands to illustrate point) level and like

518

00:53:40.510 --> 00:53:50.989

Taylor: coping with like the right now of being sleep deprived and all by myself kind (laughs) of thing. Whereas I was a bit like I don't think it is (gestures with hands to illustrate point) this. I think (laughs) it's (gestures with hands to illustrate point)

519

00:53:51.020 --> 00:53:53.760

Taylor: you know deeper than this or stuff,

520

00:53:54.020 --> 00:53:59.980

Taylor: yeah, that's not just about the fact that I'm a a new parent in the pandemic kind of thing.

521

00:54:00.780 --> 00:54:01.470

Sarah: Right.

522

00:54:01.470 --> 00:54:03.000

Taylor: But that was never really … (interrupts self)

523

00:54:03.310 --> 00:54:08.859

Taylor: and also then I didn't open up because it was just a phone (makes phone gesture with hand) like, I'm like, I don't really know you to…

524

00:54:09.090 --> 00:54:09.900

Sarah: Yeah.

525

00:54:09.900 --> 00:54:13.446

Taylor: …to kind of push this, or to kind of trust you as well, why.

526

00:54:13.700 --> 00:54:15.070

Sarah: Yeah, yeah.

527

00:54:17.190 --> 00:54:22.639

Sarah: Yeah, absolutely, there … there were kind of a couple of factors playing their part

528

00:54:22.900 --> 00:54:26.189

Sarah: as well. Yeah, but kind of a lack of exploration of

529

00:54:26.250 --> 00:54:29.449

Sarah: what your past experiences were like and that … how that might be

530

00:54:29.680 --> 00:54:36.920

Sarah: impacting you. Do you know, again (laughs), I'm asking, did you ever know the role of of the person, like what type of therapist they were, no (shakes head)

Taylor (speaking at the same time as interviewer) No.

531

00:54:36.920 --> 00:54:37.430

Taylor: No

532

00:54:38.180 --> 00:54:39.940

Sarah: Okay, okay.

533

00:54:40.920 --> 00:54:50.869

Sarah: And just circling back slightly in terms of diagnoses as well. Have you ever had a diagnosis of autism or ADHD at all?

534

00:54:51.070 --> 00:54:51.650

Taylor: No.

535

00:54:51.870 --> 00:54:59.699

Sarah: Okay, that's absolutely fine. Just just something that's been showing up in interviews that I was kind of interested in (laughs) and asking about.

536

00:55:00.587 --> 00:55:05.950

Sarah: Okay, and kind of thinking now about … more about the future.

537

00:55:06.650 --> 00:55:14.210

Sarah: Having kind of received a diagnosis of of DPDR and feeling like perhaps a bit more understanding of yourself,

538

00:55:14.260 --> 00:55:17.420

Sarah: what are your hopes for the future?

539

00:55:18.730 --> 00:55:19.390

Taylor: I think,

540

00:55:19.630 --> 00:55:30.000

Taylor: probably six months a year ago, I I would be like, I wanna get rid of this. I don't wanna do this anymore but I'm more … bit more laid back about it … about like … I think it'll probably always be part (gestures with hands to illustrate point) of me.

541

00:55:31.123 --> 00:55:37.300

Taylor: It's more … I … and I'm coming to a point of acceptance and kind of

542

00:55:37.930 --> 00:55:46.530

Taylor: trying to let it just wash over me when it does happen and not being so focused on (pauses) it being bad or shameful or

543

00:55:46.690 --> 00:56:03.140

Taylor: something I need to fix. So that's kind of my hopes and more just continue working on myself. So yeah, the bit about like, who am I (laughs and pauses) and learning to, yeah, accept that and and not be afraid of that, but that's really hard.

544

00:56:03.770 --> 00:56:10.260

Taylor: So that's that's kind of like my hope for the future, just acceptance of that

545

00:56:11.200 --> 00:56:15.110

Taylor: and being okay with feeling things.

546

00:56:16.090 --> 00:56:16.770

Taylor: Yeah. That’s what I … what I hope (spoken quietly). Yeah

547

00:56:20.570 --> 00:56:21.250

Sarah: Mmm.

548

00:56:22.360 --> 00:56:32.069

Sarah: Is there s… anything that you perhaps would like to see changed in the healthcare system to support diagnoses of DPDR?

549

00:56:32.070 --> 00:56:39.470

Taylor: (answers immediately) Yeah, I think assessment … it’s assessment. Like I wasn't … I've never been properly given the opportunity. It's been more focused on kind of the …

550

00:56:39.660 --> 00:56:44.460

Taylor: the present or the danger or the kind of like, the here and now and I do…

(internet cuts out whilst Taylor is speaking so lost some of what she was saying)

551

00:56:51.110 --> 00:56:54.509

Taylor: (internet stabilises and Taylor is finishing her sentence)…or if things got really bad, I think I would cost the NHS. Ooo did it stop?

552

00:56:54.510 --> 00:56:58.700

Sarah: Sorry you froze slightly (laughs). I don't think I caught all of that.

553

00:56:58.700 --> 00:57:07.189

Taylor: I was just saying like, I'm lucky that I can afford things because if I couldn't pay for this myself, I think I'd cost the NHS (gestures with hands to illustrate point) more because I would be in a …

554

00:57:07.980 --> 00:57:14.999

Taylor: I think I'd be by now in a really bad state and needing like serious care is where (laughs) I put it so …

555

00:57:15.780 --> 00:57:24.530

Taylor: if more was invested kind of earlier to assess and properly look (gestures with hands to illustrate point) at me as a whole, not just on particular parts of me or particular events,

556

00:57:25.320 --> 00:57:33.950

Taylor: I think that would be a lot better for me and I assume people in my situation but couldn't afford the care they needed. They'd cost more money, so …

557

00:57:34.290 --> 00:57:37.279

Taylor: it doesn't … it doesn't make sense to me is what I'd say.

558

00:57:37.610 --> 00:57:43.460

Taylor: And I'm still a bit unsure, like yeah (gestures with hands to illustrate point), I've gone and found a therapist but is there other stuff I should be doing or …

559

00:57:43.870 --> 00:57:51.500

Taylor: is there other stuff for me that I haven't found yet that I should be kind of getting care for … so it is all a bit …

560

00:57:51.750 --> 00:57:57.010

Taylor: you know, based on look as well … (pauses) which doesn't seem right.

561

00:57:59.460 --> 00:58:01.760

Sarah: Mmm, I also feel slightly struck about what …

562

00:58:02.210 --> 00:58:07.659

Sarah: what perhaps healthcare professionals, when you've gone to them like the GP, have focused on.

563

00:58:07.660 --> 00:58:08.005

Taylor: Yeah. (laughs)

564

00:58:09.230 --> 00:58:12.949

Sarah: And I wonder (pauses) is there anything …

565

00:58:13.860 --> 00:58:20.679

Sarah: you've kind of said it a little bit because you said, “ooo, they they've asked a lot.” They kind of want to know about risk and they're asking about the present.

566

00:58:20.920 --> 00:58:41.670

Sarah: Are there other things that they should be asking? Or do you feel like … (interrupts self) sorry, there's two questions here. One is kind of around, are there other things they should be asking? And number two is, do you feel like they've got a certain idea in their mind in terms…

Taylor: (interrupting and speaking over interviewer) Yeah

Sarah: …of mental health things and they're lo… almost looking at that rather than looking at things more holistically?

567

00:58:42.010 --> 00:58:49.629

Taylor: Totally, I feel completely (gestures with hands to illustrate point) channelled whenever I have spoken to them, to be like, they've already got an idea in their mind about which channel (gestures with hands to illustrate point) they're gonna send me down or

568

00:58:50.080 --> 00:58:51.550

Taylor: a solution.

569

00:58:52.513 --> 00:58:54.319

Taylor: Yeah, completely.

570

00:58:55.236 --> 00:58:58.640

Taylor: And yeah, the thing … I don't know if it's …

571

00:58:58.990 --> 00:59:04.790

Taylor: it's hard because of the the system. So at my GP’s (gestures with hands to illustrate point) anyway, I don't (shakes head) speak to the same GP every time.

572

00:59:04.890 --> 00:59:08.599

Taylor: There's like three or four, so I know some of them a bit better than others

573

00:59:08.750 --> 00:59:11.310

Taylor: but this stuff is sooo sensitive

574

00:59:11.430 --> 00:59:18.310

Taylor: and to properly (gestures with hands to illustrate point) get me to to give them (gestures with hands to illustrate point) what they need to know, I need to … I need to be able to trust that

575

00:59:18.640 --> 00:59:26.139

Taylor: you're gonna hear it and do something about it and that it's … I need trust in you, just as a human, I suppose.

576

00:59:26.290 --> 00:59:32.230

Taylor: And so part of it is that is lacking which I get (gestures with hands to illustrate point), like you know, that

577

00:59:32.300 --> 00:59:35.649

Taylor: there has to be ways of like triaging or whatever else

578

00:59:36.815 --> 00:59:47.529

Taylor: but even if there was kind of a proper assessment and exploratory (gestures with hands to illustrate point) questions asked, like I have to be able to know that what I'm gonna (gestures with hands to illustrate point) give to you is, gonna

579

00:59:48.940 --> 01:00:03.789

Taylor: be useful or done something about or like sensitively handled. Whereas I don't really have that sense. I'm more so … I probably give (gestures with hands to illustrate point) them more stuff that's easier for them to channel, if you see what I mean because I'm not gonna fully (gestures with hands to illustrate point) open up to …

580

01:00:05.290 --> 01:00:12.210

Taylor: up to them, when I know I've got 15 minutes (laughs) as well. Like appointments are 15 minutes, so it's it's not … it's not so easy.

581

01:00:13.255 --> 01:00:35.980

Sarah: Mmm, mmm so it’s something about the short (gestures with hands to illustrate point), the short time span as well. Almost with … it's the primary care part it sounds like. Like the bit when you go to the GP, is the first person that you would go to in these situations and it's a short period of time and they've got an idea in their mind and it … and you're kind of controlled and gatekeeped by them. You don't really have…

Taylor: (interrupting interviewer) Yeah

582

01:00:36.040 --> 01:00:40.599

Sarah: …the autonomy unless you go privately and you have to have the money…

Taylor: (interrupting interviewer) Yeah

Sarah: …to go privately.

583

01:00:40.600 --> 01:00:48.440

Taylor: Exactly and I get it cause they have to be experts in absolutely (gestures with hands to illustrate point) flipping everything right? And so part of me is like, should they (gestures with hands to illustrate point) be the first …

584

01:00:48.580 --> 01:00:54.679

Taylor: that you know, they're always (gestures with hands to illustrate point) mental health experts and they must deal with so many different kind of nuances.

585

01:00:55.730 --> 01:01:00.519

Taylor: So yeah, is there a better way of getting the information (gestures with hands to illustrate point).

586

01:01:00.970 --> 01:01:04.109

Taylor: out of me if you see what I mean and then them,

587

01:01:04.170 --> 01:01:09.830

Taylor: whoever in healthcare, being able to assess the right options for me, I suppose.

588

01:01:11.070 --> 01:01:11.840

Sarah: Mmm.

Taylor: Yeah

589

01:01:12.800 --> 01:01:17.690

Sarah: And if a friend was starting the journey to a diagnosis for DPDR,

590

01:01:17.740 --> 01:01:22.990

Sarah: what would you hope might be different for them? I know we've kind of covered that but anything else

591

01:01:23.060 --> 01:01:24.120

Sarah: that you'd like.

592

01:01:26.960 --> 01:01:36.329

Taylor: Yeah, I mean my advice to them is probably not go to their GP (laughs) cause of what's happened with me, but that's not right and that's not what I'd normally say for anything else … like I love the NHS and

593

01:01:36.510 --> 01:01:43.280

Taylor: fully support it, so … I don't know (pauses), yeah (pauses and looks to the side and stares into space).

594

01:01:48.850 --> 01:01:50.239

Taylor: I don't know. (turns to face the camera screen again) Yeah, I don’t know, sorry.

595

01:01:50.620 --> 01:01:55.279

Sarah: No, it's okay. I mean what you just said there about not going to the GP sort of says to me,

596

01:01:55.370 --> 01:01:58.050

Sarah: you'd hope for a GP that perhaps would be…

597

01:01:58.050 --> 01:01:59.120

Taylor: (interrupting and speaking over interviewer) Yeah, I would (nods head). Yeah (nods head).

598

01:01:59.120 --> 01:02:07.949

Sarah: …an understanding and no, you don't (shakes head) need to apologise. (gestures with hands to illustrate point) This is what I'm kind of understanding from you is is yeah, a GP who is open

599

01:02:08.010 --> 01:02:13.500

Sarah: to it rather than having an idea in their mind that this is what it is and this is what I'm gonna do

600

01:02:13.550 --> 01:02:17.599

Sarah: and maybe more time and money invested in that, as well.

601

01:02:18.280 --> 01:02:19.390

Taylor: Yeah, yeah, totally.

Sarah: Yeah

602

01:02:19.950 --> 01:02:29.610

Taylor: And the … just looking (gestures with hands to illustrate point) at the whole picture was all like DPDR, for me (points to self) anyway, isn't just sat in a bucket (gestures with hands to illustrate point) by itself. It's like, there's all sorts of other behaviours and things going on with me that...

603

01:02:29.750 --> 01:02:30.750

Sarah: Mmm, mmm

604

01:02:30.750 --> 01:02:34.719

Taylor: …when we just kind of exploring, so looking at …

605

01:02:34.850 --> 01:02:39.699

Taylor: I'd hope (gestures with hands to illustrate point) that someone'd look at someone as a whole (laughs), not just particular but…

606

01:02:40.730 --> 01:02:49.619

Sarah: Mmm, mmm and now I'm I'm going actually slightly backwards but i… just kind of came into my mind. I was thinking a little bit about

607

01:02:50.530 --> 01:02:52.020

Sarah: anxiety…

608

01:02:52.150 --> 01:02:52.750

Taylor: Mmm

609

01:02:52.750 --> 01:02:56.990

Sarah: and perhaps like your experience of anxiety.

610

01:02:59.050 --> 01:03:02.999

Sarah: Is that … is that something that you experience? Much anxiety or…?

611

01:03:03.000 --> 01:03:09.792

Taylor: We've explored that, not really. I'm a very controlled, calm person (laughs). That's probably cause I just go numb (gestures with hands to illustrate point and laughs).

612

01:03:10.350 --> 01:03:16.670

Taylor: But I don't know. I think that is part of who I am as well. I don't worry too much and I don't … (long pause)

613

01:03:19.540 --> 01:03:21.909

Taylor: like know … I do… (trails off)

614

01:03:22.130 --> 01:03:33.330

Taylor: …but we have explored, there's a part of me that when something gets really (gestures with hands to illustrate point) stressful or I can't control it, is do I get so (gestures with hands to illustrate point) anxious and that's why I numb out, like I just can't deal with it so…

615

01:03:33.330 --> 01:03:35.480

Sarah: (interrupting and speaking over Taylor) Yeah, so that might be a trigger for depersonalisation…

616

01:03:35.480 --> 01:03:35.870

Taylor: (interrupting and speaking over interviewer) Yeah.

617

01:03:35.870 --> 01:03:37.929

Sarah: …and derealisation.

618

01:03:37.930 --> 01:03:48.920

Taylor: It's almost like I can't (gestures with hands to illustrate point) d… deal with it, even the anxiety, so then I switch (gestures with hands to illustrate point) off, so am I so (gestures with hands to illustrate point) anxious (laughs) that I won't even let myself feel anxious, if you see what I mean…

Sarah: Mmm

Taylor: …so yeah, it could be that.

619

01:03:48.960 --> 01:03:50.150

Sarah: (interrupting and speaking over Taylor) Absolutely

620

01:03:50.230 --> 01:03:55.900

Taylor: But I wouldn't (shakes head and places hand on chest) say I've got anxiety or I ever feel anxious …

Sarah: (interrupting Taylor) Yeah

Taylor: …but yeah.

621

01:03:56.200 --> 01:03:58.379

Sarah: Yeah, it sounds like what you're saying is that

622

01:03:58.870 --> 01:04:07.399

Sarah: generally you're okay but there are moments which might provoke kind of a spike in anxiety which then potentially results in you

623

01:04:07.940 --> 01:04:14.479

Sarah: resorting to strategies where you shut down…

Taylor: (interrupting interviewer) Yeah (nods head)

Sarah: …because tha… that's your mode of coping…

Taylor: (interrupting interviewer) Yeah (nods head)

Sarah: …and…

Taylor: (interrupting interviewer) Yeah (nods head)

Sarah: …survival.

Taylor: Yeah

624

01:04:15.273 --> 01:04:21.619

Sarah: And in those moments then, like, that's probably what's triggering it, but then you're able to

625

01:04:21.690 --> 01:04:26.150

Sarah: reduce that anxiety and perhaps come out of those experiences, would you...

Taylor: (interrupting and speaking over interviewer) Yeah

Sarah : …agree a bit?

626

01:04:26.150 --> 01:04:28.499

Taylor: Yeah, I know that's what I'm learning to do, yeah.

627

01:04:28.500 --> 01:04:30.679

Sarah: Yeah, yeah, yeah.

628

01:04:30.700 --> 01:04:35.659

Sarah: And you mentioned you're having EMDR or you had EMDR.

629

01:04:35.660 --> 01:04:36.410

Taylor: Had it, yeah.

630

01:04:36.410 --> 01:04:41.419

Sarah: Yeah, and that that was supportive. Has that (Taylor makes a noise but can’t work out what she says)… or no?

631

01:04:41.420 --> 01:04:44.799

Taylor: It wasn't (shakes head). It was awful (laughs)…

Sarah: (interrupting Taylor) Oh

Taylor: …so we had to stop, so (laughing)

632

01:04:45.400 --> 01:04:45.730

Sarah: Okay.

633

01:04:45.730 --> 01:04:51.840

Taylor: So apparently I had one of the most violent reactions to EMDR that my therapist…

Sarah: (interrupting and speaking over Taylor) Okay

Taylor: …has ever seen in 20 years, so… (trails off and laughs)

634

01:04:54.095 --> 01:04:54.420

Sarah: Oh wow! (Taylor continues laughing) Wow.

635

01:04:54.420 --> 01:05:02.289

Taylor: Up to that. I think it’s something…

Sarah: (interrupting and speaking at same time as Taylor) What happened?

Taylor: …I can't remember what … she said something in my reptilian brain (touches back of head), it's so powerful that (gestures with hands to illustrate point) we should probably just leave (laughs),

636

01:05:03.220 --> 01:05:05.010

Taylor: just not go there kind of thing.

637

01:05:05.670 --> 01:05:07.430

Sarah: Mmmhmm, mmmhmm.

638

01:05:07.610 --> 01:05:19.779

Sarah: So that was actually a really challenging experiencing them. So is there any … cause it sounds like, what … what else have you been doing with your therapist apart from EMDR?

639

01:05:19.780 --> 01:05:27.087

Taylor: We've done a bit of C … CBT and then it's mainly been like holistic (gestures with hands to illustrate point) just talking … talking, I suppose.

640

01:05:28.380 --> 01:05:31.088

Taylor: I've been keeping things like diaries

641

01:05:31.960 --> 01:05:36.492

Taylor: and starting to do, like more … it's around (pauses)

642

01:05:37.620 --> 01:05:46.310

Taylor: like shame, compassion to myself (points to self with hand) and like different techniques (demonstrates tapping with hands on chest) like tapping and meditation …

643

01:05:46.450 --> 01:05:51.619

Taylor: mi … like mindfulness and things like that. Trying to just calm (gestures with hands to illustrate point) myself down a bit, I suppose.

644

01:05:52.810 --> 01:05:53.700

Sarah: Mmmhmm, mmmhmm.

645

01:05:53.820 --> 01:05:54.910

Sarah: Okay

646

01:05:55.190 --> 01:06:01.460

Sarah: And and has that felt helpful in reducing the depersonalisation and derealisation?

647

01:06:01.890 --> 01:06:04.220

Taylor: I think the most useful thing has been…

648

01:06:04.390 --> 01:06:07.239

Taylor: it's yeah, the diary and the kind of …

649

01:06:07.680 --> 01:06:26.069

Taylor: the awareness and checking in with myself and then being able to unpack (gestures with hands to illustrate point) like situations cause one … when I've … I've gone (gestures with hands to illustrate point) and said, "oh, this has happened, and it's made me like really angry", and when we unpack (gestures with hands to illustrate point) it, it's like, I'm not angry actually, I'm just really really sad and … but my way of dealing (gestures with hands to illustrate point) with it has been anger and then I've kind of like trigger (gestures with hands to illustrate point) myself into just

650

01:06:26.810 --> 01:06:39.559

Taylor: switching off. So being able to talk (gestures with hands to illustrate point) through and work out how … like I just can't identify how I feel quite a lot of the time. So having someone where I can work (gestures with hands to illustrate point) that through has been the most helpful thing.

651

01:06:40.380 --> 01:06:44.851

Sarah: Mmm, okay. Well thank you, that's really helpful.

652

01:06:46.240 --> 01:06:48.659

Sarah: Is there anything else that you think

653

01:06:48.780 --> 01:06:55.210

Sarah: is important to tell me about your experience or anything that you think I haven't asked?

654

01:06:58.660 --> 01:06:59.979

Taylor: I don't think so.

655

01:07:02.530 --> 01:07:03.330

Taylor: No (shakes head).

656

01:07:03.530 --> 01:07:07.530

Sarah: Okay, in that case, I'm gonna stop the recording then (smiles).

657

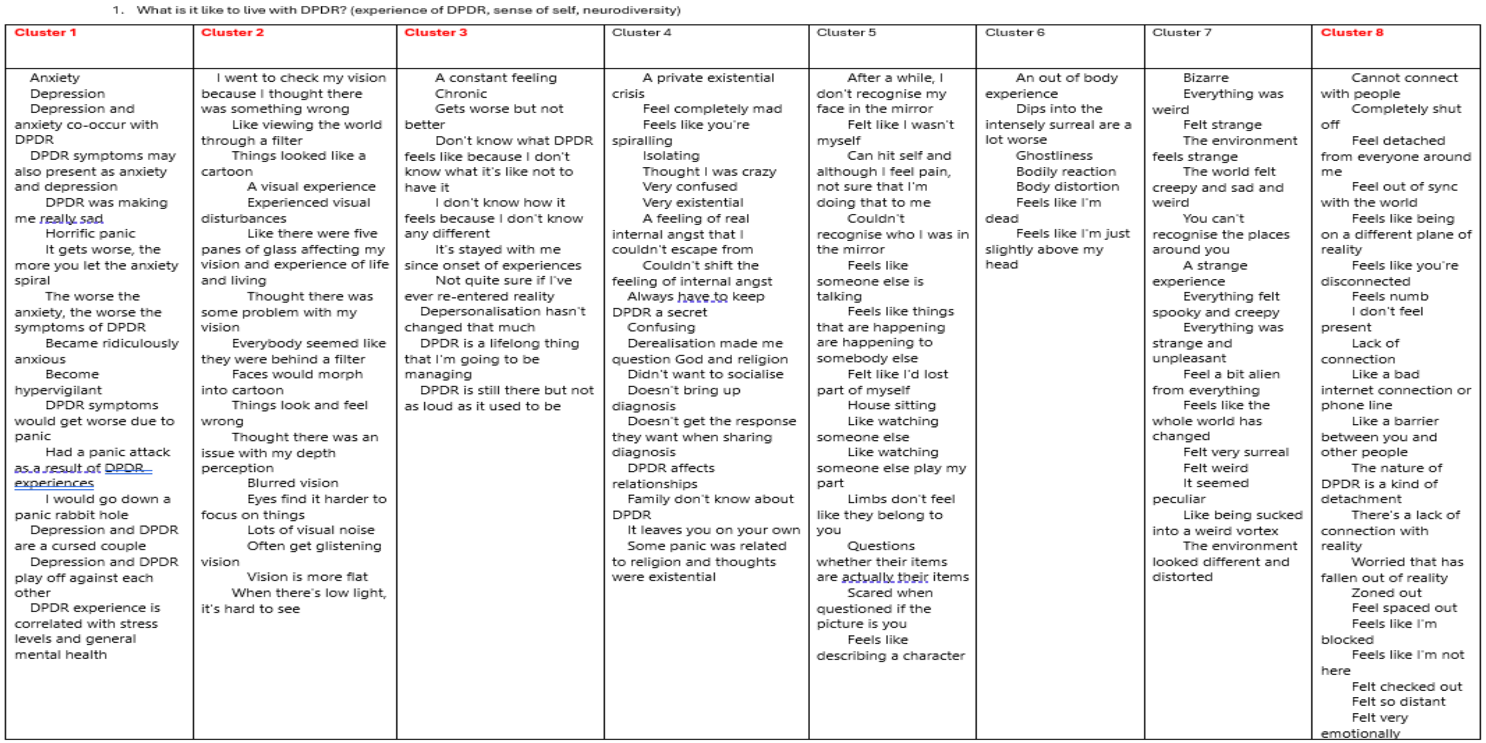
01:07:07.530 --> 01:07:08.090

Taylor: Okay.

Appendix P

Thematic analysis coding stage 2

This is an example of how the initial codes identified in the interview transcripts were organised into clusters that addressed the research questions and aims. Clusters highlighted in red identified key codes.



1. What is it like to live with DPDR? (experience of DPDR, sense of self, neurodiversity)

Cluster 1	**Cluster 2**	**Cluster 3**	Cluster 4	Cluster 5	Cluster 6	Cluster 7	**Cluster 8**
Anxiety Depression Depression and anxiety co-occur with DPDR DPDR symptoms may also present as anxiety and depression DPDR was making me really sad Horrific panic It gets worse, the more you let the anxiety spiral The worse the anxiety, the worse the symptoms of DPDR Became ridiculously anxious Become hypervigilant DPDR symptoms would get worse due to panic Had a panic attack as a result of DPDR experiences I would go down a panic rabbit hole Depression and DPDR are a cursed couple Depression and DPDR play off against each other DPDR experience is correlated with stress levels and general mental health	I went to check my vision because I thought there was something wrong Like viewing the world through a filter Things looked like a cartoon A visual experience Experienced visual disturbances Like there were five panes of glass affecting my vision and experience of life and living Thought there was some problem with my vision Everybody seemed like they were behind a filter Faces would morph into cartoon Things look and feel wrong Thought there was an issue with my depth perception Blurred vision Eyes find it harder to focus on things Lots of visual noise Often get glistening vision Vision is more flat When there's low light, it's hard to see	A constant feeling Chronic Gets worse but not better Don't know what DPDR feels like because I don't know what it's like not to have it I don't know how it feels because I don't know any different It's stayed with me since onset of experiences Not quite sure if I've ever re-entered reality Depersonalisation hasn't changed that much DPDR is a lifelong thing that I'm going to be managing DPDR is still there but not as loud as it used to be	A private existential crisis Feel completely mad Feels like you're spiralling Isolating Thought I was crazy Very confused Very existential A feeling of real internal angst that I couldn't escape from Couldn't shift the feeling of internal angst Always have to keep DPDR a secret Confusing Derealisation made me question God and religion Didn't want to socialise Doesn't bring up diagnosis Doesn't get the response they want when sharing diagnosis DPDR affects relationships Family don't know about DPDR It leaves you on your own Some panic was related to religion and thoughts were existential	After a while, I don't recognise my face in the mirror Felt like I wasn't myself Can hit self and although I feel pain, not sure that I'm doing that to me Couldn't recognise who I was in the mirror Feels like someone else is talking Feels like things that are happening are happening to somebody else Felt like I'd lost part of myself House sitting Like watching someone else Like watching someone else play my part Limbs don't feel like they belong to you Questions whether their items are actually their items Scared when questioned if the picture is you Feels like describing a character	An out of body experience Dips into the intensely surreal are a lot worse Ghostliness Bodily reaction Body distortion Feels like I'm dead Feels like I'm just slightly above my head	Bizarre Everything was weird Felt strange The environment feels strange The world felt creepy and sad and weird You can't recognise the places around you A strange experience Everything felt spooky and creepy Everything was strange and unpleasant Feel a bit alien from everything Feels like the whole world has changed Felt very surreal Felt weird It seemed peculiar Like being sucked into a weird vortex The environment looked different and distorted	Cannot connect with people Completely shut off Feel detached from everyone around me Feel out of sync with the world Feels like being on a different plane of reality Feels like you're disconnected Feels numb I don't feel present Lack of connection Like a bad internet connection or phone line Like a barrier between you and other people The nature of DPDR is a kind of detachment There's a lack of connection with reality Worried that has fallen out of reality Zoned out Feel spaced out Feels like I'm blocked Feels like I'm not here Felt checked out Felt so distant Felt very emotionally

							disconnected from my family and friends I was in my own world I'm present and able to communicate with people but also not If I think about it too much on an existential level, I feel disconnected from the world around me Lack of awareness and presence Disconnect between own actions DPDR made it difficult to recognise being physically unwell due to disconnection from body
Cluster 9	Cluster 10	Cluster 11	Cluster 12	**Cluster 13**	Cluster 14	Cluster 15	Cluster 16
Cognition and memory are not great Derealisation messes with your memory Felt foggy It's like a haze Brain fog Brain is switched off Can't remember movements Disorientating Get frustrated because I forget things Like head goes to complete mush Memory is blurry and you're not sure what you said or did Not able to function very well Poor concentration	Convinced I was in a dream Didn't know where the nightmare ended and reality began Like being in a movie Like being watched on a television show	Depersonalisation and derealisation experienced in dreams Dreams about being a ghost Felt like I was having very disturbing nightmares	Experiences have got worse with ageing The sensation of depersonalisation increases with age	Extremely freaked out Makes you terrified A very harrowing experience Felt like hell Felt very bad It was very scary It's horrible Severe and debilitating Felt like my brain was shearing in half DPDR caused lots of distress DPDR feels slightly sinister DPDR runs on the fearful feeling that is triggered by DPDR	Feels like I'm not safe A loss of control Not in control of what I'm doing Not in control of the DPDR	Felt like I was a robot Like being on autopilot No emotions Speaking feels automated Don't feel pain DPDR doesn't always allow me to feel things Feel nothing It's upsetting because I can't feel everything fully Like my brain turns worries and feelings off	I don't exist Like everything is not real Not grounded in reality Questions whether things exist World doesn't exist Would describe it as lack of realness Actions are meaningless Felt like I had been deleted from the system If I haven't spoken to or seen somebody in a while I question my reality Question the reality of your experiences

Brain can't deal with life and that keeps DPDR going Can't remember wedding day Don't remember big parts of daughter's childhood Don't remember giving birth to three of my children DPDR has stopped me working DPDR prevented me from doing anything at all Had to pause studying as a result of DPDR Recently recovered from being a recluse				Friends were terrified and thought I had lost my marbles It's been the bane of my life The scariest thing is the unknown			Questions whether people exist Thought that this can't be real A sense of separateness from others Connect with body when doing something risky Can feed into more risky decisions Didn't care about actions because there was no consequence if things weren't real Sometimes I don't believe that DPDR exists
Cluster 17	**Cluster 18**	Cluster 19	Cluster 20	Cluster 21	Cluster 22	Cluster 23	Cluster 24
Perception of time is messed up Things are happening in a slight time delay You're getting images but they're a little bit delayed Everyone around me was still moving and I wasn't	Protective Felt like I had a superpower DPDR is like a superpower DPDR protected from the feelings of depression DPDR state was helpful at times Get through things if I operate in DPDR state I can be more thankful towards DPDR than angry My brain was protecting me from me My brain was trying to make sense of what was going on	Like walking around in a bubble Felt like being in a fishbowl Felt like I was in a snow globe Hearing made me feel like I was in a box	Clear sense of self Always had clear sense of self as an adult Got more understanding of myself	Does not have a clear sense of self Lack of gender clarity Not always had a clear sense of self or identity You don't feel an identity Because of borderline personality disorder I have a muffled idea of what my identity is I don't know what makes me happy I don't know who I am Struggled with sense of self and identity	I thought I wasn't good enough Sense of self affected by early abuse experiences Sense of self has been affected by life experiences Always been an outsider Always been self-reliant As a child told couldn't do anything good Didn't put any value on considering my own needs as they weren't considered by others Felt that I was other because I was mixed race Had to survive rather than explore self	Sense of self has been affected by DPDR DPDR forced me to get to know myself and have a different outlook on life DPDR is a big part of me During a bad episode of DPDR wasn't sure who I was I don't ever feel like there was a me before DPDR Knowing myself has reduced the depersonalisation sensations No sense of individuality impacted on depersonalisation derealisation experiences	Being a part of a group created an identity Developed sense of self through therapy I have veered towards an identity of who I am in my relationship with God I wouldn't know who I am without my relationship with God Working through the derealisation has helped establish a clearer sense of self

					I didn't know that I was a person and could say no In childhood, developed negative beliefs about self, exacerbated by borderline personality disorder Made to feel like an object No sense of a place I grew up in which contributes to DPDR Ongoing identity issues as a child Sense of self changed when reaching secondary school Sense of self developed in teenage years Trauma creates a grim version of the self You feel like a toy of your Dad	Questions what self would be like without DPDR Sees self as third person Self is external from who I am Feeling out of sync is attributed to queerness and neurodivergence Intersecting identities can affect DPDR	
Cluster 25	Cluster 26 (coping)	Cluster 27	Cluster 28	Cluster 29	Cluster 30	Cluster 31 (internet)	Cluster 32
Sense of self affected by autism	Able to notice when it's happening Awareness of DPDR experiences Being able to recognise it Once you know what is going on, the nature of DPDR changes Radical acceptance is important Try to accept DPDR rather than think about my symptoms Try not to give DPDR too much attention	Live in the present Uses grounding techniques Animals are helpful with grounding Focused on my body I finally have a toolbox to carry with me whcih enables me to deal with distressing situations Plays musical instrument Scheduled once a week video calls with friends Sign up to receive emails from different	Addiction can help you with comfort, connection and control Addiction gives you back physiological connection that is missing with DPDR Hypothesises that some people with DPDR cope by using drugs or alcohol in order to feel something Smoking marijuana help me connect with what I was feeling and made it more normal	Cut out caffeine Cut out things that make you feel worse Do some exercise Get some good sleep Incorporated things back into my life Stop partying and neglecting my mental health Stopped drinking alcohol	Always connected to God Been going to church Concentrated on being a Jehovah's witness Concentrated on religion Have a relationship with religion and God Having religion is protective	Did a whole bunch of research which became unhealthy at some point Internet searching normalised the DPDR experience People are screaming for help online People who suffer from DPDR are a kind of community online without even realising	On the internet, people propose crazy theories which aren't helpful People are susceptible to what they're being told on the internet The internet is the source of so much pain and anguish because people are trying to find solutions

	Awareness of sensation being around for a long time Be compassionate with myself Become more understanding of it Been able to learn how to live with DPDR Don't do anything to try and change the experience Facing up to the reality rather than running from it Let go of DPDR and let the autopilot do its thing More awareness of why it is happening Need to constantly understand what was going on Offer myself reassurance The more I notice DPDR, the more I can respond to it and work on grounding and being more present Try to check in with myself Try to let the DPDR feelings flow through me Worked out my triggers Radical acceptance of the DPDR that people have to battle with Nowadays can recognise being depersonalised	websites to remind of existence Used DBT techniques Uses mindfulness type techniques Uses musical instrument to ground self and regulate breathing When I smell food, it means I'm on the same plane of reality Wrote a diary		Stopped using drugs and substances Take care of myself Try to live life as normally as possible Try to reduce stresses in my life	My relationship with God keeps me grounded Pray a lot	Periodically googled and came across term depersonalisation derealisation Reddit and social media is people's main means to getting answers Started researching what is this The biggest source of diagnosis is Reddit The internet explained DPDR experiences that I couldn't put into words Used the internet to learn more about DPDR Using the internet to educate myself on DPDR Became part of forums like DP self-help Friend researched DPDR experience described on the internet Had to discover things online because professionals couldn't explain DPDR Looked at DPDR online Looked online and found an article talking about DPDR Looking up experience of depersonalisation and derealisation online	There are problematic forums for people with DPDR

						was the first time I heard of DPDR People with DPDR experiences have been cast adrift to find their own answers on the internet Saw facebook groups of people experiencing DPDR Stumbled upon derealisation online The DPDR explanation I found online was the first time I connected with something	
Cluster 33	Cluster 34						
Hard to describe Hard to explain It's hard to tell people what's wrong Questions expectation for others to grasp what DPDR means Reluctant to bring up diagnosis of DPDR	Mum brushed off concerns about my DPDR Mum thought I was crazy Mum thought I was ill when I told her how I was feeling						

2. What factors affect the development of depersonalisation and derealisation?

Cluster 1	Cluster 2	Cluster 3	Cluster 4	Cluster 5	Cluster 6	Cluster 7	Cluster 8
Anxiety is caused by DPDR but also triggers DPDR Anxiety and DPDR feed off each other Anxiety built up triggering DPDR experiences DPDR started after having a panic attack Stress Theorises that DPDR is an anxiety system built in by childhood experiences Believes depersonalisation is a freeze and dissociate response Believes that detachment is brains predetermined reaction to stress and anxiety Believes that they were susceptible to DPDR as a reaction to stress and anxiety DPDR triggered by the build up of stress by being away from home for university Experienced DPDR for the first time as a child during panic Feeling very nervous triggered DPDR state Growing up feeling on edge can make you more prone to anxiety and DPDR experiences It was a form of social anxiety	A lot of aggression Developmental trauma Experience of abuse Experienced violence in the house Trauma is a big trigger for DPDR Underlying trauma kept causing DPDR to bubble to the surface Links DPDR experiences before sleeping with sexual abuse which happened in bed Dad was often angry Emotional needs not met Experienced verbal abuse Loud screaming fights Parents argued all the time Physical abuse was punishment Physically abused by Mum Saw a few violent things Shouting in the house Trauma Domestic violence Experience of psychological abuse Parents pushed and shoved each other Police had to come round due to argument between Mum and her partner	Bad school experiences in the UK Every morning would wake up anxious about going to school Socially anxious a lot of time in school Always came home crying from school Always had problems at school with friends during teenage years At school in the UK, my presence did not go down well Children wanted nothing to do with me Completely ostracised Didn't want to start school Dropped out of school Everything was a bit too much at school Got anxious about going to school or starting new schools Got stomach sick at school during the day Memories of distress in school Not a good student Struggled at school Would cry when Mum dropped me at school Zoned out in school due to anxious and obsessive thoughts	Felt afraid Remember the sensation of not feeling safe A sense of fear and uncertainty was passed on Earliest memories are of a lack of safety Everything was very tense Felt scared all the time since five or six years old Lonely Very isolated At home I was upset Grew up feeling on edge Grew up in highly pressured environment I was always scared of sleeping Lacked mental and emotional security Never emotionally supported Things felt frightening When got upset was not noticed	Chased it backwards through time Think I had DPDR when I was younger too Approximately aged 3 or 4 when started experiencing DPDR symptoms At eight years old Brief experience of DPDR as a child due to reading an upsetting story Childhood DPDR experiences triggered by illness First DPDR experience was as a freeze response during childhood First experience of DPDR age 11 or 12 Probably had DPDR for a long time Episodic experiences of DPDR symptoms during childhood Childhood experience of not existing state Some experiences of this kind of detachment as a very young child	DPDR experiences exacerbated by drugs Started after smoking marijuana Triggered by eating hash brownies Weed is a big trigger for DPDR Believes that cannabis smoking was a conduit to trigger DPDR which probably would have happened anyway Believes that chronic weed smokers are like to develop DPDR over time Use of substances triggered relapse of DPDR Neglecting my mental health and partying triggered relapse of DPDR Was working hard and partying hard which combined with other things triggering DPDR	Environment change is a trigger for DPDR experiences New environments and circumstances can change DPDR experience or make it worse Transitioned to secondary school which was anxiety provoking and scary DPDR can be triggered by transitions with people DPDR is triggered whenever anything different that is out of my schedule shifts Moved cities and DPDR got really bad The symptoms developed in anticipation of moving country Transition stage caused anxiety about the future Believes that childhood DPDR experience may have been triggered by being in a new and unfamiliar place Anticipation of something new was scary	The switches flipped When things were difficult, I switched off from myself DPDR is not something that you can switch off

Not knowing that you're having a panic attack is an easy route into derealisation Scared and anxious for months prior to moving country for university degree Trying to be present increases awareness of DPDR which then increases stress Panic Anxiety on top of past trauma Believes that DPDR is a big part of complex PTSD Stacked up to anxious and nervous collapse Stress and DPDR experiences are linked When I get very anxious I feel more numb	Sexually abused by father at a young age There were constantly fights and arguments Husband was manipulative and verbally abusive						
Cluster 9	Cluster 10	Cluster 11	Cluster 12	Cluster 13	Cluster 14 (neurodiversity)	Cluster 15	Cluster 16
Transiency didn't help with strengthening social bonds	DPDR onset at Christmas of first year of university DPDR experiences started three years ago DPDR has been weaving in and out of life for a decade First noticeable time was the day I got married Onset of DPDR at age 18 Onset of DPDR at age 19 Onset of DPDR at age 20 Onset of DPDR at age 26 Onset of DPDR at age 30	House burgled age 17 Parents divorced or split up during childhood Parents used me and my brother to attack each other Treated like a friend by parents and they've shared too much A whole mess of surgeries over 3 years Been used by parents in lots of ways Bullied a little bit Dad kidnapped brother Dad left when I was about 2 years old Dad only came into my life when I was eight years old Experienced various levels of poverty I was a support system for both my parents	Initial experiences in the church were foundations for depersonalisation and derealisation Left the church completely Being told that existence is dependent on this religious group Brought up with religion being an important part of life Damaging friendships growing up in the church environment Deeply connected to religion as a child Grew up in an intensely	Struggling with mental health OCD Had religious OCD Bulimic behaviour around 16 or 17 Got into a cycle of restricting food and then binge eating and then falling into guilt shame mindset Had eating disorder since I was about 13 I was generally a child who got quite anxious and stressed Mentally exhausted and always thinking about food	ADHD diagnosis Autism diagnosis Neurodivergence ADHD is also linked with complex PTSD Brother thinks that Dad might be autistic Diagnosed with ADHD about a year ago DPDR is closely linked with ADHD Explored an autism diagnosis Have always had ADHD traits Mother and Grandmother have ADHD diagnoses	Always good relationship with Mum Good relationship with Mum Good relationship with Dad Good relationship with parents and siblings Good relationships with grandparents Grew up in a good family dynamic Happy as a kid Mum and Grandma were key people Childhood was happy to an extent Grandma visited every six months for	Dad would disappear Dad was strict and clean Dad was the breadwinner Didn't get to spend much time with Dad Difficult relationship with Mum because things were hard Distanced from grandparents Mum put me under pressure Not a good relationship with Dad Dad didn't want to deal with children and homelife

	Onset of DPDR during first year of university Started to notice DPDR as a problem around the time gave birth to daughter	I was restrained Lived between Mum and Dad's house Lived in lots of houses Lots of medical issues over my life More intensive surgeries in early teens Moved around a lot during childhood Moved from South Africa to the UK Moved home suddenly at a young age Mum and Dad hated each other Mum had OCD Mum would often go out and leave us Panic attack caused by people fighting on the street and coming into my house Parents divorce was messy and volatile Parents have problems with alcohol Parents struggled financially People broke into our house Problematic surgeries between age 10 and 13 Restrained over and over again Sometimes would stay in hostels or with family Stress around money was palpable Stressed parents There would be an argument over anything Was kicked out of friendship group by best friend Would get woken up in the middle of the night and get taken somewhere	fundamentalist religious environment Religious trauma Bigger trauma to leave the church and community	Poor mental health throughout childhood and teenage years Struggled with eating disorder behaviours from age 9 or 10 Was suicidal as a teenager Diagnosis of an eating disorder Diagnosis of complex PTSD Diagnosis of phobia Diagnosis of postnatal depression Ended up having psychotic depression Panic attacks were most prominent between ages 15 to 18 Postpartum depression	One of my children is autistic People at school thought I had ADHD Psychotherapist told me to seek diagnosis for ADHD Some parts of ADHD overlap with DPDR Thinks that ADHD traits may have been a contributing factor for DPDR experiences Throughout my life there were autistic traits Two of my children have ADHD	the majority of childhood Grandparents were like our second parents Intense and loving relationship with Mum Mum was great Positive experiences of spending time with Grandmother Was closest to Mum	Dad disciplined us more than Mum Dad is not okay Dad was absent from childhood Dad was an addict to many things Dad was miserable Dad was stressed Dad would shout at me and my siblings Lack of emotional connection with Dad Lack of trust in parents My parents were wrapped up in their own stuff Parents did not meet my needs When Dad isn't working, he's constantly drinking

Cluster 17	Cluster 18	Cluster 19	Cluster 20	Cluster 21	Cluster 22	Cluster 23	Cluster 24
Did well academically in high school Had good friends in school Had many friends in high school Positive school experiences	Don't remember many things in childhood Childhood was a bit chaotic Childhood was a bit all over the place Disconnected from the people who were supposed to look after me Don't think I had a normal childhood Had a very unstable childhood Had to rely on myself Home life was stable until teenage years Home life was up and down I'm disconnected from my childhood Independence encouraged from a young age If cried would be asked to get it together Lots of instability during childhood Mixed bag of childhood experiences No sense of my house Teenage years were very stressful The house felt turbulent There was constant tension There would always be chaos Unsettled home life when parents divorced In the past, will rely on myself Teenage years were not so good	Moved cities during childhood which changed family dynamics	All Mum's partners had a lot of issues Mum's partner got addicted to alcohol Experience of homophobic abuse from Mum's partner Experience of infantilisation Mum's partner was a bigot Mum's partner was a nightmare Mum's partner was controlling Mum's partner was not nice towards me for example name calling Mum's partner was racist My Mum and Step Dad's actions didn't make sense to me Remember not being a nice environment at home with Mum's partner and his family Stepdad was an alcoholic Stepmother put me on diets and told me I was fat Stepmother was both kind and cruel which was confusing Stepmother was cruel	Couldn't cope with feelings when having stomach issues Had lots of investigations done at the hospital to find out what was wrong with my stomach No one connected anxiety and stomach issues	I was a bit weird as a child Struggled to fit in socially Very sensitive Was introverted Told that I never spoke Was quite shy	Separation anxiety from Mum Experience of separation anxiety	Wet the bed until aged 11 or 12

3. How has the journey through the healthcare system with DPDR been experienced? (journey in healthcare system)

Cluster 1	**Cluster 2**	**Cluster 3**	Cluster 4	**Cluster 5**	**Cluster 6**	**Cluster 7**	Cluster 8
A convoluted journey Did not get anywhere with diagnosis in the NHS Journey in the healthcare system has been a mess Messed around by the NHS Been through a lot of therapists Consulted with three different healthcare providers Continuity of health care professionals is a challenge DPDR diagnosis took longer than other diagnoses Experience of healthcare system being confused and lost Getting the diagnosis was a faff Going to uni resulted in discharge from adult mental health services In the perinatal mental health team, I saw different members of the team i.e. psychiatrist, psychologist, nursery nurse and support worker Journey has taken almost four years Lack of consistent care via the GP My clinician went on sick leave	A diagnosis meant it was something I could now work with A diagnosis meant there was something I could research A diagnosis of DPDR meant there was a path to answers and understanding the experience Diagnosis of DPDR brought understanding to the situation Diagnosis of DPDR meant that I felt I wasn't going crazy Diagnosis of DPDR validated what had been through DPDR diagnosis could provide understanding of self DPDR diagnosis provided opportunity for self-compassion Receiving a diagnosis was a relief The DPDR label feels helpful A diagnosis has allowed me to give myself a break A diagnosis is the gateway to getting out A diagnosis meant I could stop searching for answers A diagnosis meant I had evidence of what I had Diagnosis means that things regarding my mental health are now easier to get done	A wait for assessment On waiting list for the well-known centre for DPDR for six months The wait for assessment felt long The wait for help is not feasible There was a wait for every step in the process There's a waiting list for therapy on the NHS 2 year wait for intervention with the well-known centre for DPDR, following assessment 9 month wait for assessment at well-known centre for DPDR Approximately 2 years between going to GP and getting seen by the well-known centre for DPDR Approximately a one year wait for assessment with the well-known centre for DPDR Getting a diagnosis took just over a year Long wait and process to get treatment Long wait to see a psychiatrist Put on waiting list for CBT with local wellbeing team	Accessed help through GP In the NHS, your GP is the interface with the system Asked GP about referral for therapy Believes that by luck had a GP who was willing to refer to mental health services Believes that doctors want to manage the issue themselves in primary care rather than referring onwards Couldn't be referred by your GP to the well-known centre for DPDR GP didn't want to address DPDR because was seeing therapist GP wasn't very helpful Had tried to get referral from the NHS to the DPDR clinic on many occasions, but this was not successful Lack of accessible pathway to mental health services	Accessed psychologist privately Diagnosis of DPDR received privately NHS did not meet needs so accessed private therapist Once I found private support, I stuck with them GP encouraged to go privately if this was affordable Had to get help privately in order to get help specifically for DPDR Had to go private in order to be seen quickly I'm lucky that I can afford private help Met with psychiatrist a week or two after accessing private support My parents supported me to find a private service Not a long wait for private care Private wait was much better than the NHS Saw a private CBT therapist Settled on a private professional who confirmed diagnosis of DPDR Under lots of services but continued to pay for private therapy because it wasn't helping	Medication caused more numbness Medication didn't improve symptoms Medication made me feel more detached Tried sertraline which heightened my senses and made DPDR worse Don't think medication is helpful Haven't found any medication that has treated or alleviated the actual symptoms of DPDR Medication stopped me crying as much but maybe this wasn't helpful Medication was reinforcing DPDR Quetiapine masked the DPDR Quetiapine helped the dissociation because it took the feelings away from my body Sertraline made all the weird symptoms worse Sertraline made my mental state worse Venlafaxine made the DPDR even worse	Prescribed antidepressants to help reduce anxiety and feel calmer Prescribed Lamotrigine Psychiatrist chose medication for me Citalopram was the best medication I've had that stops me getting panic moments Doctor put me on medication and sent me home Escitalopram has been good I was offered medication a lot Prescribed and took Quetiapine Prescribed sertraline by doctor Prescribed Venlafaxine in an attempt to fix or help the DPDR Taking escitalopram for DPDR Tried medications for DPDR such as Sertraline and Citalopram Tried every medication under the sun	Took antidepressants for about six months

Overall it's been a back and forth journey for three and a half years Poor experience of support and care from the NHS Stressful process Taken 15 years to get diagnosis of DPDR The healthcare system is problematic The journey to receiving a diagnosis took a while There's so many hoops to jump through to be seen for anything Tried a few different places to get seen and a DPDR diagnosis Tried different therapists but most weren't familiar with DPDR so weren't helpful Tried various times to get a diagnosis and understanding of DPDR Under lots of services Wellbeing team had to prove that they had give me all the help that they could Wellbeing team referred on to the well-known centre for DPDR Went through the NHS process which resulted in discharge to stew	Diagnosis meant DPDR was officially recognised Diagnosis meant that I had support from healthcare professionals Diagnosis provided clarity Diagnosis was a light bulb moment DPDR diagnosis meant I could get help for DPDR DPDR diagnosis helped to feel seen Needed a diagnosis in order to get help	Six months between completing therapy with the NHS and being seen for assessment at the well-known centre for DPDR Six week wait for first session from the wellbeing service The healthcare system is not responsive enough to people with DPDR experiences The long wait was communicated by a group in the NHS The NHS tried to convince me that a long wait was fine There was quite a long wait and I had to chase them Waited a few weeks for assessment You have to chase up mental health services all the time		When I went privately, the psychiatrist was more receptive to my case Worries about the NHS journey in the future if wasn't able to afford private as no official diagnosis has been recorded			
Cluster 9	**Cluster 10**	**Cluster 11**	Cluster 12	Cluster 13	**Cluster 14**	**Cluster 15**	**Cluster 16**
Believes that clinicians think that they know what the issues is and they are going to stick with that	Completed CBT but this did not change the experience of the depersonalisation and derealisation	Believes that DPDR remains a medical mystery	Can feel like you're getting shunted through a binary	Diagnosis is present on GP record Diagnosis provided via letter	Diagnosis of DPDR received from the well-known centre for DPDR Had in-person assessment session	DPDR was mislabelled Given diagnosis of PTSD Misattributed to trauma Misattributes to another diagnosis	Felt like I couldn't get help due to lack of understanding and lack of resources

Believes that doctors don't really want to hear about DPDR experiences Clinicians were very dismissive Concerns and experiences dismissed No one was listening Clinicians believe that I'm using thoughts as a buffer against feelings and so wouldn't consider DPDR experiences Clinicians were kind of meh about it Hand waved away DPDR experience and concerns Local mental health team refused further treatment for DPDR as didn't offer this or think it was needed despite recommendations from the well-known centre for DPDR Took five or six years for DPDR to be taken seriously	Did tapping therapy Given EMDR Offered CBT for DPDR Offered group CBT or individual CBT which was unhelpful Taught grounding exercises Therapeutic intervention for DPDR was unhelpful Therapy has mainly been talking There's not a specific treatment for DPDR Well-known centre for DPDR gave specialised talking therapy with elements of CBT Been doing mindfulness techniques CBT taught me a lot about anxiety but didn't reduce DPDR Did embodying experiences as an intervention EMDR and Tapping therapy were helpful EMDR was unhelpful Experience of therapy for DPDR was chaotic and unpredictable Had psychotherapy through the NHS Had sessions with psychologist for 12 weeks Had an assessment and then 12 sessions with the wellbeing team Initially only received a six week intervention The support received was counselling or CBT counselling The therapy was more about tackling the anxiety underneath the DPDR	Lack of awareness of DPDR amongst mental health professionals Lack of knowledge about what to do with DPDR Lack of knowledge amongst professionals Lack of professional knowledge prevented diagnosis Lack of understanding about DPDR from GP's Questions whether clinicians understand something else better The main factor preventing a diagnosis is the lack of knowledge on DPDR amongst professionals There's no one ready to listen who has knowledge about DPDR Thinks that clinicians don't really know about DPDR Psychiatrist googled which medication to give me for DPDR The only thing the GP knew what to do was to prescribe medication Appeared to be a confusion from professionals about what constitutes a diagnosis of DPDR Believes that nobody knows exactly what causes DPDR Believes that nobody knows exactly what will cure DPDR	Feels like the doctor is working through a flowchart Believes that the NHS works in a practical textbook way which doesn't work for mental health If you don't fit into the box, you can't access support No one fits into these boxes so we're setting everybody up to fail The service contradicts itself by saying you have to fit into a box but everyone is different When you're not appropriate to receive support with a certain team, it makes you question your experience of DPDR With DPDR, you're never going to fit in the box You have to fit into a box	Diagnosis has been completely ignored Diagnosis not listed on appointment summary letters DPDR diagnosis was received verbally The NHS removed my DPDR diagnosis Received DPDR diagnosis around the age of 21	following initial telephone session at the well-known centre for DPDR Had therapy with the well-known centre in the UK for DPDR Referred to the well-known centre in the UK for DPDR Engaged in therapy with the well-known centre for DPDR Given specialist treatment for dissociation from the well-known centre for DPDR Had a telephone assessment session initially from the well-known centre for DPDR I was disappointed by the well-known clinic for DPDR Just finished therapy with the well-known centre in the UK for DPDR Mental health team pushed for me to be assessed at the well-known centre for DPDR Offered treatment with the well-known centre for DPDR The depersonalisation service got me out of a crisis and helped me cope again rather than fixing DPDR	All other mental health conditions diagnosed at the same time as DPDR symptoms were prominent Believes that mental health professionals think I'll be okay if the anxiety is reduced DPDR and anxiety diagnosed at the same time DPDR experiences were seen as an anxiety condition DPDR is linked to my other diagnoses Felt frustrated with professionals because the low mood was caused by DPDR and it was a vicious cycle GP thought I had anxiety Had to pull therapists away from thinking about trauma Has diagnosis of borderline personality disorder If you tell people there's trauma in your background, they assume you want trauma healing It went through a lot of other things first Other mental health diagnoses received when started to try and get diagnosis for DPDR Professionals attributed dissociative experience to stress and worry Professionals presume that DPDR is some form of psychosis Psychologist told me that my derealisation experiences could be a result of borderline personality disorder	Lack of resources in the NHS One specialist clinician trying to provide assessment and therapy Only one specialist DPDR clinician Avoided NHS mental health services due to being slow and oversubscribed Believes that funding and resources aren't dedicated to the understanding of DPDR Definite sense that professionals don't have the resources available to work with DPDR Difficult to open up in a 15 minute appointment Doesn't think that there's much support available for DPDR General NHS mental health services are oversubscribed General NHS mental health services are slow Hypothesises that a postcode lottery impacts how DPDR is seen and treated Hypothesises that the structure of the NHS could be preventing DPDR diagnoses No support available in the local mental health team Professionals didn't feel skilled to work with DPDR The NHS is rushed Type of care received is based on postcode Use up lots of resources in the healthcare system

		Clinicians are vaguely aware of DPDR DPDR was more complicated to understand because there wasn't anybody able to explain it to me Earlier diagnosis and treatment could have been achieved if there was somebody in the local mental health team that had an understanding of DPDR Got the diagnosis but no help was available Had hoped that there would be specialised treatment or a cure It was exhausting telling my story over again and them not understanding GP's had to google what DPDR is No one explained DPDR diagnosis and said you have to wait for the treatment No one ever said that dissociation existed No one knew what was going on Professionals weren't sure about the neurology of DPDR or the full set of symptoms Psychiatrist did some googling about depersonalisation Therapist understood dissociation rather than DPDR specifically Lack of understanding				Questions whether it's easier for professionals to term the difficulties PTSD rather than DPDR Suggested that DPDR was a result of purely obsessional OCD Tried to treat other mental health conditions with the hope it would improve DPDR Went to GP who said it was dehydration	

Cluster 17	Cluster 18	Cluster 19	Cluster 20	Cluster 21	Cluster 22	Cluster 23	Cluster 24
Had counselling at university which wasn't very good	Had experiences but didn't always get a formal diagnosis No formal diagnosis of DPDR	Lack of understanding and awareness of DPDR is frustrating and invalidating Lack of understanding, knowledge and awareness did more damage than good Lacking a treatment or cure for DPDR added to my hopelessness Because therapy didn't help I felt more anxious and like a lost cause Believes that because mental health professionals don't know DPDR, they don't want to approach it Feels frustrating that it sits apart from other diagnoses Felt like I couldn't be cured Felt that I was literally without help I was left to my own devices If people don't understand, you back away from the support Lack of acknowledgment of DPDR diagnosis is really frustrating Lost hope Not pursued a diagnosis because there's no known treatment or intervention for DPDR	Psychiatrist did a thorough assessment	Psychologist was able to name depersonalisation and derealisation experiences and disorder Psychologist was amazing Psychologist was based at GP surgery so got to see them straight away Psychologists only people who recognised it The psychologist at the baby group was the first person who didn't just tell me to forget about the fact I couldn't remember my daughter's birth Therapy with psychologist was helpful	Believes that the NHS didn't want to use the resources or the funding they had for a lesser understood condition	Did therapy with local borough and then requested specialist help	Didn't feel like the help I got was what I needed

		There wasn't any treatment available for DPDR Questions if professionals don't understand, whether people will understand DPDR experience					
Cluster 25	Cluster 26	Cluster 27	Cluster 28	Cluster 29	Cluster 30	Cluster 31	Cluster 32
Gendered expectations about how to present with a mental health issue	I don't know what support I should be accessing I've given up	I should have been diagnosed with anxiety as a teenager I should have had a proper assessment when I was younger	Information in healthcare letters was contradictory	Little bits of therapy for DPDR far apart	Made to feel too much by professionals Needed validation but didn't get this	New therapist is fully understanding DPDR	Sent away to do some reading on DPDR

4. What are the hopes for the future of understanding DPDR? (future guidance)

Cluster 1	Cluster 2	**Cluster 3**	Cluster 4	**Cluster 5**	**Cluster 6**	**Cluster 7**	Cluster 8
A clearer path to noticing and assessing DPDR Hope for increased awareness of DPDR and its symptoms Hope to be met with a level of understanding More knowledge of DPDR Professionals to be more aware of how common DPDR is Understanding of how DPDR presents Understanding that what is a normal experience for people without DPDR won't be for people with DPDR Don't brush DPDR off as something else GP's should be more aware of DPDR Hope for recognition of link betwen DPDR and anxiety amongst health professionals More understanding would have helped me to feel less insane Need to be aware of the causes of DPDR People who work in mental health need to realise that DPDR is a real thing	Coming to a point of acceptance Understanding that acceptance is the only way of moving forwards and therapy should be focused on this	Don't react in a shocked manner to people explaining their situation Need to be able to trust that healthcare professionals will listen and act People with DPDR need someone they can trust and who can offer reassurance Have to know that the conversation is going to be sensitively handled Health professional should not make people feel like they're crazy Validate the experience of DPDR	Explain more about DPDR Explain what's happening in your body when experiencing DPDR Explain what's happening in the brain when experiencing DPDR It would be good for doctors to explain DPDR immediately and offer reassurance Would like to know what's happening to the brain when experiencing DPDR Provide clarity on DPDR	Have the time to listen to someone's story Listen to all the person's experiences and then narrow down from there Get the stories about how DPDR affects people Look at me as a whole, rather than just particular parts or events Clinicians to be empowered to move away from the flow chart and acknowledge many different possibilities Have a different approach or strategy to other disorders because DPDR is harder to conceptualise It's okay for people not to fit in the boxes Services that treat the individual	Hope that people will have the ability to ask for help and get it Need a proper system to help people experiencing DPDR Point in the right direction and try to help Support available when asking for help To have tangible support for DPDR If you are under the wrong service, don't be put on another waiting list Needs quicker, simple answers and guidance For people to know straight away that there is help out there Go to the psychiatrist and get a diagnosis Have to know that the support is going to be useful Help should be accessible via the Internet, GP, helplines or a therapist When somebody reaches out for support with DPDR, that there's hope for them	More education on DPDR Need more research on DPDR Professionals should do more reading about DPDR Research on DPDR can help many lives More studies that include people suffering with DPDR Qualitative research goes a long way There is a wealth of knowledge to research about DPDR For professionals to check with someone more knowledgable if they don't understand DPDR Hope for information to be disseminated re DPDR Increase research through charities It might be helpful to have required seminars for health professionals on DPDR Mental health professionals must be willing to learn and change	People who need support for DPDR should not be cast adrift to find their own answers on the internet Information on DPDR needs to be accessible for people who are having experiences of DPDR People shouldn't have to dig to find out about DPDR Want people to know what's going on from the beginning of DPDR experience

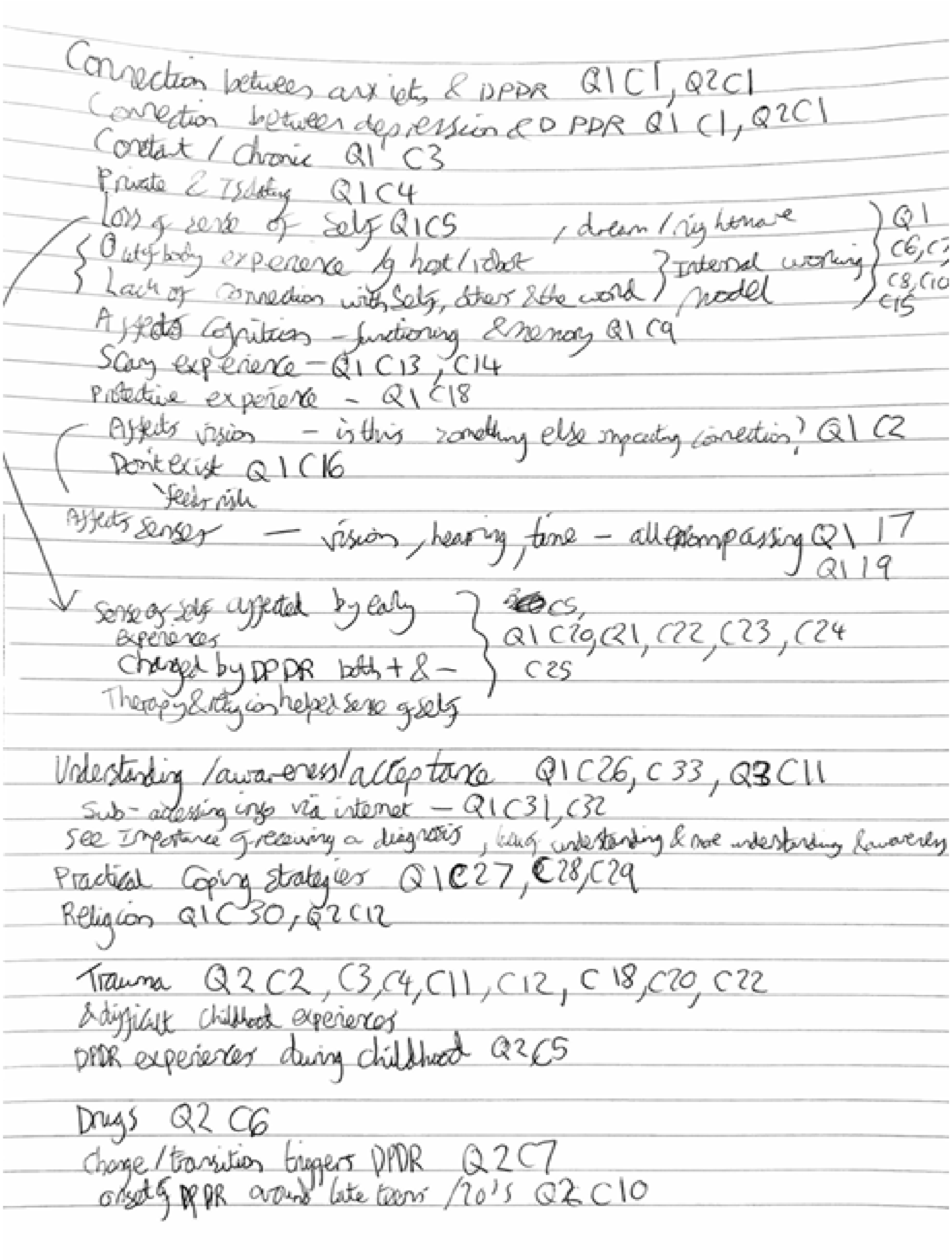
Cluster 9	Cluster 10	**Cluster 11**	**Cluster 12**	Cluster 13	**Cluster 14**	Cluster 15	
Having DPDR as a buzzword will increase awareness and help make support accessible Would like DPDR to become a buzz word that people know More campaigns that raise awareness of DPDR More public messaging regarding DPDR	Ideal would be that they find a treatment that fixes DPDR Develop techniques to better manage DPDR I hope that there's a point of full recovery	Invest more in assessing DPDR GP's need more time Better healthcare resources For there to be more specialist clinics or services available in the UK so that you don't have to sit on a waiting list for the well-known centre for DPDR Hope for other DPDR hubs to be set up Would like joined up care	Maybe do some CBT as a therapeutic intervention Recommend doing EMDR as a therapeutic intervention Address depression or pre-existing anxiety prior to DPDR Recommend a whole therapy with every single type of therapy Therapy shouldn't focus on the deep psychological stuff and dredging things up from the past Try tapping	Admit that the wait isn't good and offer other options	Consider the best way of getting information to support diagnosis of DPDR Create a better way to identify DPDR for more people Early diagnosis will stop it getting out of hand Early diagnosis will stop the search for answers online It would make a difference if there was better diagnosis of DPDR	GP's should still refer to mental health services even if there is a long waiting list	

Appendix Q

Thematic analysis coding stage 3

The researcher looked at the different clusters and summarised the theme of each cluster. The researcher then looked at which clusters related to each other and how this developed into a larger theme. This is detailed below.

Figure Q1



Connection between anxiety & DPDR Q1C1, Q2C1
Connection between depression & DPDR Q1 C1, Q2C1
Constant / chronic Q1 C3
Private & Isolating Q1C4
Loss of sense of self Q1C5 , dream / nightmare
Out of body experience eg host / robot
Lack of connection with self, others & the world } Internal working model } Q1 C6, C7 C8, C10 C15
Affects cognition – functioning & memory Q1 C9
Scary experience – Q1 C13, C14
Protective experience – Q1 C18
Affects vision – is this something else impacting connection? Q1 C2
Don't exist Q1C16
feels [illegible]
Affects senses – vision, hearing, time – all encompassing Q1 17
Q1 19
Sense of self affected by early experiences
Changed by DPDR both + & –
Therapy & religion helped sense of self } C5, Q1 C20, C21, C22, C23, C24 C25

Understanding / awareness / acceptance Q1C26, C33, Q3C11
Sub- accessing info via internet – Q1C31, C32
See importance of receiving a diagnosis, being understanding & more understanding & awareness
Practical Coping strategies Q1C27, C28, C29
Religion Q1C30, Q2C12

Trauma Q2C2, C3, C4, C11, C12, C18, C20, C22
& difficult childhood experiences
DPDR experiences during childhood Q2C5

Drugs Q2 C6
Change / transition triggers DPDR Q2C7
onset of DPDR around late teens / 20's Q2C10

Mental health difficulties Q2 C13, C23

Neurodiversity Q2 C14

& grandparents
Positive relationships with parents growing up Q2 C15
Negative relationships with parents growing up Q2 C16

Positive childhood experiences Q2 C17

Messy Journey seeking help Q3 C1, C4, C28

Importance of receiving a diagnosis Q3 C2

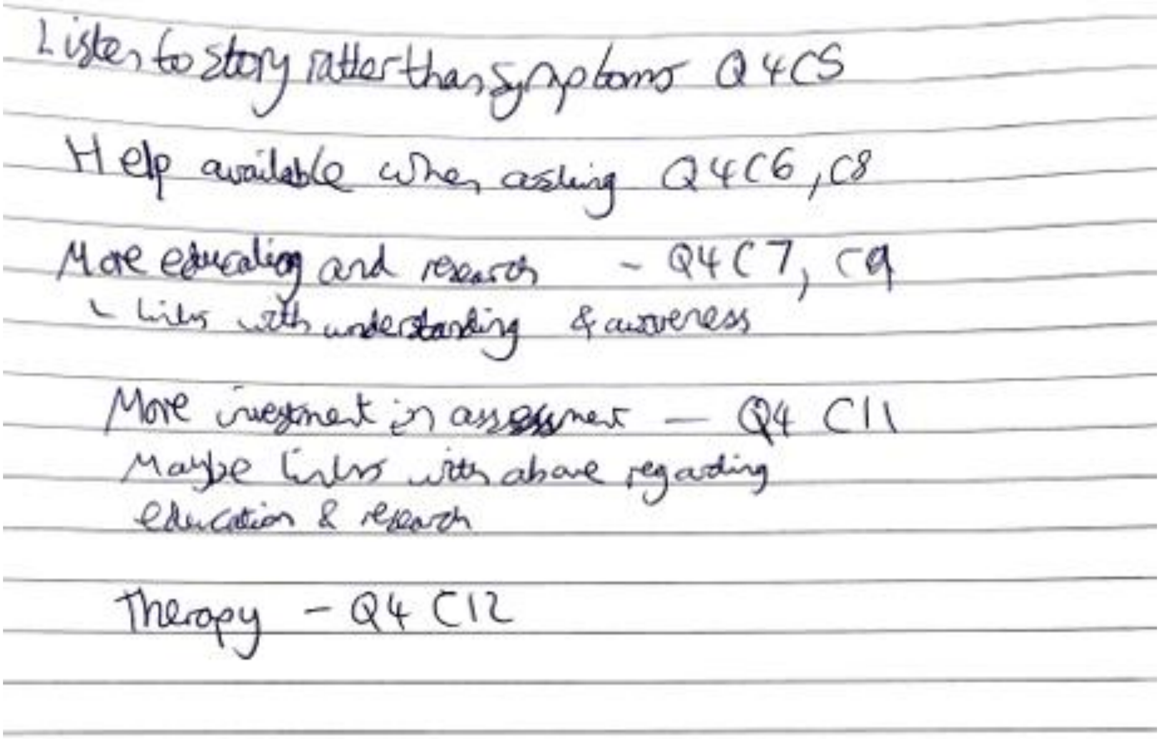
/resources
Sub-theme wait Q3 C3, C16
Sub-theme private Q3 C5
Sub-theme dismissive Q3 C9
Medication - Q3 C6, C7, C8

Intervention (links with medication)
Q3 C10

Lack of understanding Q3 C11, C12, C15, C19
mislabelling
Diagnosis Q3 C[illegible], C18

Specialist DPDR - Resources) Q3 C14, C16
psychologist able to recognise DPDR - Q3 C21

More understanding and awareness Q4 C1, C2, C14
& better diagnosis
Sensitivity Q4 C3
More explanation of DPDR Q4 C4



Listen to story rather than symptoms Q4C5

Help available when asking Q4C6, C8

More education and research - Q4C7, C9
└ Links with understanding & awareness

More investment in assessment — Q4 C11
Maybe links with above regarding
education & research

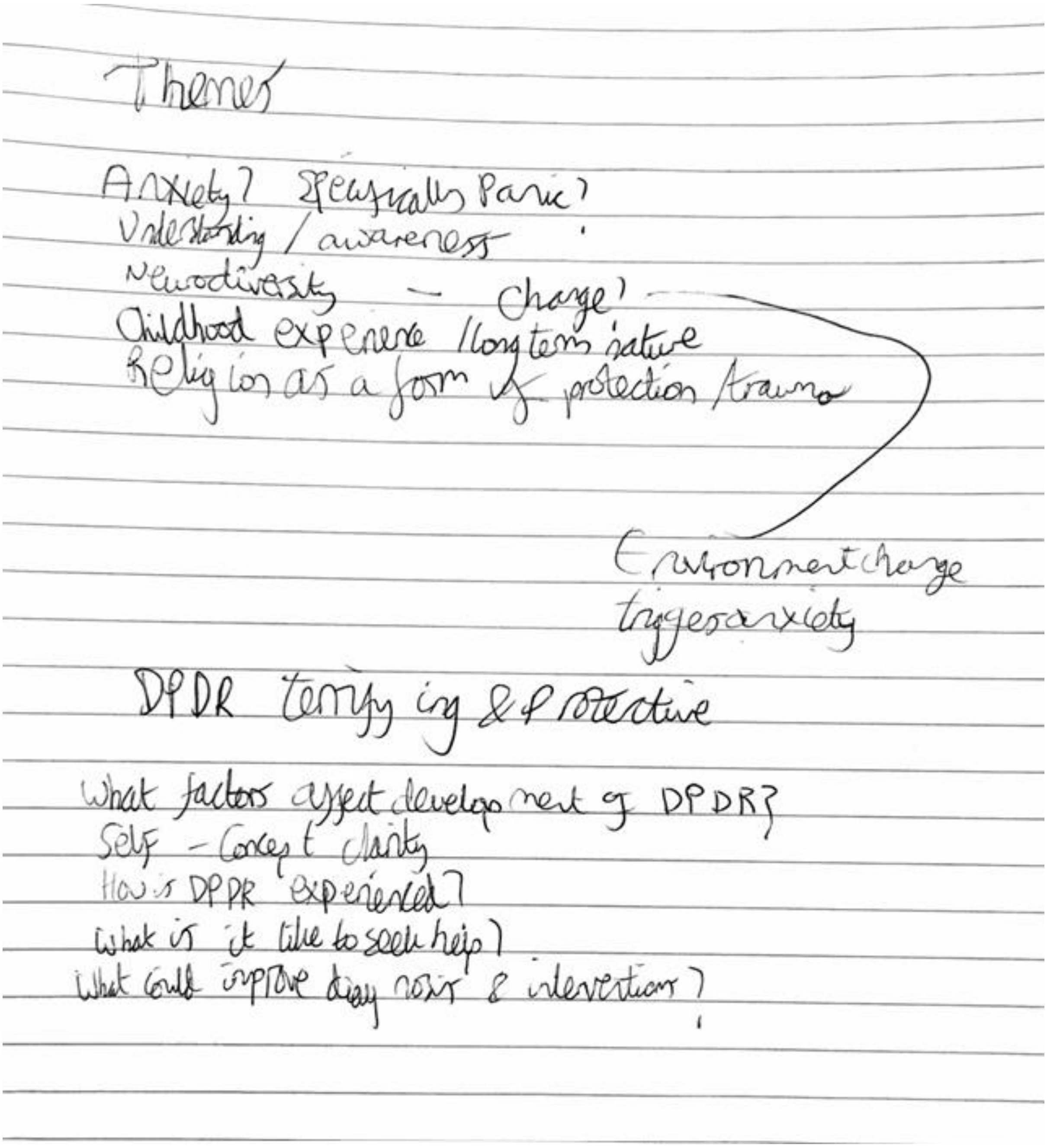
Therapy - Q4 C12

Appendix R

Thematic analysis coding stage 4

The researcher reviewed the similar ideas and began to develop themes (Figure R1). These themes were then reviewed, defined and labelled (Figure R2).

Figure R1



Themes

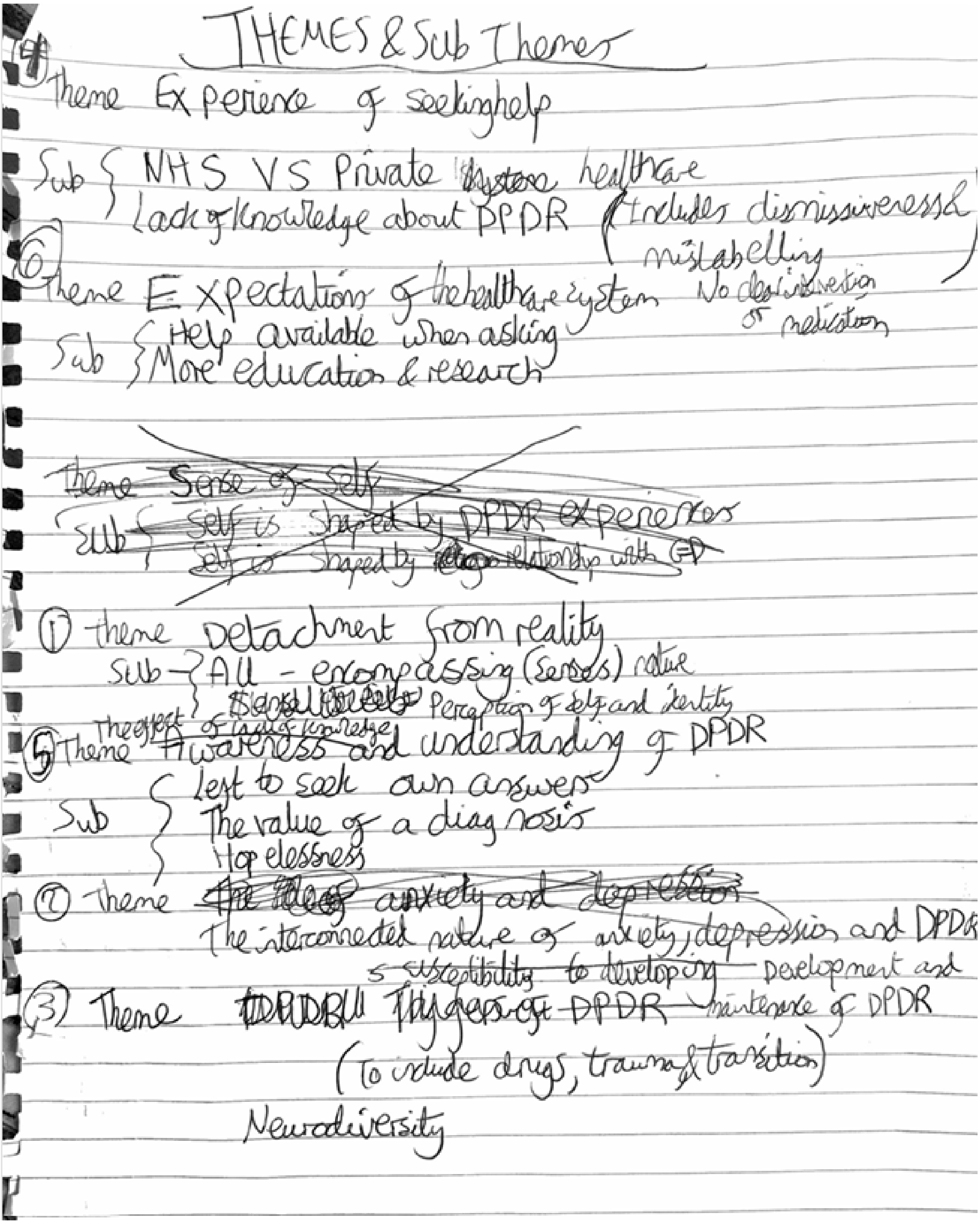
Anxiety? Specifically Panic?
Understanding / awareness
Neurodiversity – change?
Childhood experience / long term nature
Religion as a form of protection / trauma

Environment change
trigger anxiety

DPDR terrifying & protective

What factors affect development of DPDR?
Self-concept clarity
How is DPPR experienced?
What is it like to seek help?
What could improve diagnosis & intervention?

Figure R2



THEMES & Sub Themes

④ Theme Experience of seeking help

Sub { NHS VS Private ~~system~~ healthcare
Lack of Knowledge about DPDR (Includes dismissiveness & mislabelling)

⑥ Theme Expectations of the healthcare system No [illegible] of medication
Sub { Help available when asking
More education & research

~~Theme Sense of Self~~
~~Sub { Self is shaped by DPDR experiences~~
~~Self is shaped by religion relationship with GOD~~

① theme Detachment from reality
Sub – { All - encompassing (senses) nature
~~[illegible]~~ Perception of self and identity

⑤ Theme The effect of lack of knowledge Awareness and understanding of DPDR
Sub { Left to seek own answers
The value of a diagnosis
Hopelessness

② Theme ~~The role of anxiety and depression~~
The interconnected nature of anxiety, depression and DPDR

③ Theme ~~DPDR~~ ~~Triggers of DPDR~~ ~~susceptibility to developing~~ Development and maintenance of DPDR
(To include drugs, trauma & transition)

Neurodiversity