

MATTHEW E. J. WILKINSON BA Hons MSc

INVESTIGATING CLINICIANS' UNDERSTANDINGS
AND OPINIONS REGARDING DISSOCIATIVE SEIZURES,
AND EXPLORING THEIR EXPERIENCES OF PROVIDING
INTERVENTIONS FOR INDIVIDUALS WITH THIS
CONDITION.

Section A: Professionals' opinions, understandings and
experiences regarding Dissociative Seizures: a systematic review
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MRP Portfolio Summary

Section A

A systematic literature review concerning the understanding and opinions of relevant clinicians regarding dissociative seizures, and their experiences of working with this client group. Findings indicated that there was an inconsistent and limited understanding of DS, and that clinicians could harbour inaccurate and stigmatising views. Limited sample representativeness and use of unvalidated questionnaires were prominent methodological issues. Clinician education and greater acceptance of the uncertainty that arises from attempting to treat DS is indicated. Future research should make greater use of qualitative methodologies to achieve greater depth of understanding, and there should be further consideration of therapist experiences.

Section B

A qualitative study exploring the experiences of CBT therapists delivering a structured CBT intervention within the context of an ongoing randomised controlled trial. Semi-structured interviews were conducted with twelve therapists, and transcripts were analysed using Thematic Framework Analysis. The analysis suggested that the clinicians observed a considerable degree of clinical complexity in their clients, but that could effectively apply the manualised approach. Nevertheless, they perceived limitations, suggested there was a need for flexibility, and held that successful interventions must be formulation-driven. These findings will be used alongside those from the RCT in a process of triangulation.

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Section A

**Professionals' opinions, understandings and
experiences regarding Dissociative Seizures: a systematic review**

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Abstract

Dissociative seizures appear to arise from a complex combination of biological, social and psychological factors. While increasing research has focused on this area in recent years, DS remains poorly understood and the evidence-base for treatment is limited. Individuals with DS have reported feeling stigmatised as a result of their condition, and have reported negative experiences with healthcare professionals. This review sought to explore research concerning the understanding and opinions of relevant clinicians regarding DS and its treatment. Furthermore, this review also sought to examine the literature regarding clinicians' experience of working with individuals with this condition. A search of Medline, PsychInfo, Web of Science and Google Scholar identified 16 relevant papers. Some significant methodological limitations in both survey and interview-based studies were identified. Findings suggested that there are significant limitations and differences of opinion regarding professionals' understanding of DS and some professionals reported a low level of confidence in working with the condition. Stigmatising views were present among clinicians, and these may have related to limited training or clinician frustrations. Research recommendations included a need for more nuanced, qualitative research in this field, and a need for studies that consider the experiences and opinions of psychological therapists.

Keywords: Dissociative seizures, Psychogenic nonepileptic seizures, treatment, stigma, clinicians

Introduction

Dissociative seizures (DS) involve a sudden, involuntary attack of symptoms that may superficially resemble epilepsy, but are not observed to have abnormal electrical activity associated with epilepsy (Wiseman & Reuber, 2015). They are the commonest functional neurological disorder encountered by neurologists (Reuber, Howlett, Khan, & Grünewald, 2007; Stone et al., 2010a). Functional neurological disorders involve the presence of symptoms associated with neurological disorder, while lacking a corresponding structural abnormality in the brain (American Psychiatric Association, 2013).

While DS have been observed to exhibit visible symptoms that may aid neurologists in their differentiation from epilepsy (Avbersek & Sisodiya, 2010) the 'gold standard' for diagnosis is considered to be the use of video electroencephalogram (video-EEG), in which the presence or absence of epileptiform brainwave activity can be established during a seizure (LaFrance, Reuber & Goldstein, 2013). Prevalence estimates indicate that DS may affect up to 21,000 people in the UK (Benbadis, 2000). Evidence suggests that DS may be both more chronic and more impactful than epilepsy: health-related quality of life has been observed to be lower in people with DS than in epilepsy (Szaflarski et al., 2003; Karakis et al., 2014), and long-term outcomes suggest individuals with DS are less likely than people with epilepsy to reach seizure cessation (Reuber et al., 2003). Qualitative research has highlighted the debilitating, isolating and restrictive experience of living with the condition (Dickinson, Looper & Groleau, 2011; Green, Payne & Barnitt, 2004).

Categorical and etiological complexity of the condition

Dissociative seizures are thought to arise from a poorly understood interaction of biological, social and psychological factors (Brown & Reuber, 2017). Due to the influence of early psychoanalytic thought, psychological accounts of DS have traditionally been favoured in explaining the onset of DS. The enduring influence of psychoanalytic thought is reflected in modern systems of diagnostic classification.

Within the fifth edition of the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-V), DS fall under the category of 'Conversion Disorder (Functional Neurological Symptom Disorder)' (APA, 2013). Breuer and Freud introduced the term 'conversion', claiming that medically unexplained symptoms arise from the avoidance of distressing emotions through 'dissociating' from them and 'converting' them into physical symptoms (Breuer & Freud, 1957; Brown, Cardeña, Nijenhuis, Sar & van der Hart, 2007). Under the International Classification of Diseases (ICD-10), the term 'dissociative convulsions' is employed to describe DS (WHO, 1992). 'Dissociation' has its roots in the work of Janet, who claimed that such symptoms (including 'convulsive fits' (Janet, 1907)), arose from psychological processes becoming 'dissociated' from consciousness under conditions of stress (Van der Hart & Horst, 1989). Such processes may intrude on motor control when triggered by stimuli (Brown & Reuber, 2016).

Contemporary research into psychological factors associated with DS suggests that the condition is associated with higher rates of past trauma and abuse when compared with individuals with epilepsy (Kaplan et al., 2013), though a recent review suggested that methodological issues prevent firm conclusions on this matter, and that trauma does not appear to be necessary for the development of DS (Brown & Reuber, 2016). Evidence also suggests that DS may be associated with the somatic

and physiological symptoms of panic and anxiety, though the subjective experience of such anxiety may be lacking (Galimberti, et al., 2003; Goldstein & Mellers, 2006; Reinsberger, Perez, Murphy & Dworetzky, 2012). A psychological model of the condition that has emerged from such observations is the 'panic-without-panic' model: that is, that such seizures arise as a result of autonomic arousal, but without individuals being subjectively aware of this arousal (Goldstein & Mellers, 2006).

An alternate psychological model – the 'Integrative Conceptual Model' holds that medically unexplained symptoms arise as a result of the 'chronic activation of stored representations in memory' (Brown, 2004, p801). The model emphasises the selective and constructive nature of subjective experience: that subconscious cognitive processes govern which sensory data is attended to, and how that data is interpreted (Brown, 2004). Stored representations of illness may arise from factors such as the experience of illness, observation of illness or sociocultural ideas regarding illness. In the case of DS, particular sensory inputs or internal cues such as heightened arousal or trauma memories may trigger the activation of the 'seizure scaffold' – a particular kind of stored representation (essentially the 'idea' of a seizure) (Reuber & Brown, 2016). The seizure scaffold may have its roots in various factors including hardwired reflexes, experience or observation of epileptic seizures or prior physical illness.

Evidence for an association between DS and physiological abnormalities has led some experts in the field to dispute the primacy of psychological accounts of DS causation (Stone et al., 2011). While the absence of epileptiform characterises DS, there is evidence of neurological abnormality in individuals with DS, such as reduced neuronal connectivity (Xue et al., 2013). Other physiological abnormalities have also been observed, including deficiency in neuropeptide Y – a neurotransmitter associated

with stress resilience (Winterdahl et al., 2017). Moreover, DS have been observed to emerge in individuals following brain surgery (Reuber, Kral, Kurthen, & Elger, 2002).

The diverse conceptualisations, classifications and etiological assumptions concerning DS are reflected in the inconsistent terminology used to describe the condition. 'Non-epileptic seizures', 'Psychogenic seizures', 'Dissociative convulsions' and 'Non-epileptic attack disorder' have all been employed (Stone et al., 2003). Some terms such as 'pseudoseizures' and 'hysterical seizures' have been found to be offensive to some individuals with the condition (Stone et al., 2003).

Current treatment options and best practice

Following a suspected first seizure, guidelines provided by the National Institute for Clinical Excellence (NICE) (2016) recommend individuals are screened by primary care physicians, then referred for differential diagnosis by a 'specialist medical practitioner'. Neurologists typically perform this role. Best practice advises the use of video-EEG to exclude the presence of epileptiform activity during seizures (LaFrance et al., 2013). Following a diagnosis of epileptic seizures, NICE guidelines (2016) advocate a further referral to psychological or psychiatric services 'for further investigation and treatment'. Best practice psychiatric assessment should include a consideration of relevant developmental history, trauma and social context (LaFrance et al., 2013).

The precise nature of psychiatric or psychological treatment is not specified by NICE guidelines, reflecting gaps in the current evidence-base and a lack of clinical consensus (LaFrance et al., 2013). While there have been some trials of the use of

medication in the treatment of DS (LaFrance et al., 2014), there is currently limited evidence for psychopharmacological treatment of DS (Perez & LaFrance, 2016). Research has focused on treatment of the condition with psychological therapy. Despite some promising findings regarding the use of CBT to treat DS, (Goldstein, 2010), a review concluded that there is at present insufficient evidence regarding the use of psychological interventions, and that 'there continues to be very little high-quality evidence on which to base treatment decisions for people with non-epileptic attacks' (Martlew et al., 2014).

Stigma and dissociative seizures

People with DS have reported feeling stigmatised and marginalised as a result of the condition and the nature of the diagnosis. Some individuals with this condition have reported feelings of shame and embarrassment regarding their seizures, and have described the experience of being judged by others when seizures have occurred in a public place (Rawlings, Brown, Stone & Reuber, 2017). Moreover, other qualitative researchers have reported that the suggestion of an underlying psychological etiology causes individuals to endure the stigma associated with mental illness, and that this suggestion can conflict with their sense of identity (Karterud, Knizek & Nakken, 2009; Robson & Lian, 2017). Quantitative research suggests that individuals with DS report significantly higher levels of perceived stigma than those with epilepsy (Rawlings et al., 2017).

Evidence suggests that there may be a relationship between the experience of stigma among mental health service users and the perceived views of healthcare providers. The perception that mental health providers hold stigmatising views has

been found to be associated with both the 'internalisation' of mental health stigma (i.e. an individual associating themselves with negative mental-health-related stereotypes), and a sense of disempowerment among mental health service users (Wang et al., 2017). Such findings do not provide evidence that perceived stigma causes internalized stigma and disempowerment, nor do they demonstrate that such attitudes are necessarily present among professionals. Nevertheless, evidence suggests that stigmatising attitudes regarding individuals with mental health difficulties are indeed present among healthcare professionals (Hansson, Jormfeldt, Svedberg, & Svensson, 2013), and that such professionals do not exhibit less stigmatising views than the general public (Schulze, 2007).

Negative experiences with healthcare professionals

A significant body of qualitative research suggests that individuals with DS can have unhelpful or unsatisfying interactions with healthcare professionals (Rawlings & Reuber, 2016). A sense of not being properly understood is commonly reported, with some individuals feeling that they have been blamed by professionals for having DS, or accused of malingering (Robson & Lian, 2017). One study that asked participants to report their worst healthcare experience in relation to DS found that the three most frequently cited encounters were with non-epileptologist neurologists, Accident and Emergency doctors and Accident and Emergency nursing staff (Robson & Lian, 2017).

The experience of receiving the diagnosis of DS is reported as threatening for some individuals, and encounters with the diagnosing clinician could be experienced as fraught and defensive (Karterud et al., 2009). One study that applied a conversation analysis methodology to diagnostic appointments concluded that in cases where

individuals are resistant to receiving a diagnosis of DS, doctors may experience this as a challenge or threat to their medical authority (Monzoni, Duncan, Grunewald & Reuber, 2011). In some cases, individuals have reported feeling disregarded or neglected by clinicians following diagnosis (Dickinson, Looper & Groleau, 2010), with unclear treatment plans and poor communication from healthcare professionals contributing to feelings of isolation and abandonment (Fairclough, Fox, Mercer Reuber & Brown, 2013).

Previous reviews and rationale for present review

At present, the available literature suggests that DS is a complex, poorly understood condition with a limited evidence-base to support treatment options. Individuals report difficult experiences in seeking treatment and support for this condition, and the attitudes and practice of healthcare professionals can be a contributing factor in generating feelings of frustration and stigmatisation. It therefore seems crucial to consider the level of understanding among relevant healthcare professionals regarding DS, and to examine their opinions and attitudes regarding individuals with this condition. An increased understanding of clinicians' perspectives on DS may help to clarify why it is that individuals with this condition do not feel that services support them with their difficulties.

An existing review that included a consideration of healthcare providers' opinions regarding the diagnosis of DS was identified (Sahaya, Dholakia, & Sahota, 2011). This was not a systematic review: only two papers were included on this subject. Similarly, no systematic reviews of clinician opinions or understanding regarding the broader category of functional neurological symptoms or medically unexplained symptoms were identified. In view of this, it was felt that it would be

beneficial to undertake a systematic review of clinicians' attitudes and opinions regarding DS. Specifically, the present review aimed to answer the following two questions:

- 1) What understanding and opinions do clinicians have regarding DS and its treatment?
- 2) What view do clinicians have regarding individuals with DS, and what experiences do they report of working with this client group?

Methodology

In view of the limited ability of a meta-analytic approach to integrate findings where methodological diversity is present, a narrative review approach was adopted (Baumeister, 2013). This review was informed by PRISMA standards for reporting systematic reviews (Moher et al., 2009).

In line with comparable reviews in this field (e.g. Brown & Reuber, 2016), a systematic search of Medline, PsychInfo and Web of Science databases was performed. An additional hand search of reference lists and Google Scholar was performed. These searches were performed in January 2017, and included all publications published at any point from the database's creation. The search terms were kept broad in view of the diverse terminology employed to describe DS: ((staff* or clinician* or worker* or therapist* or neurologist* or neuropsychologist* or neuropsychiatrist* or nurse* or psychotherapist* or doctor* or psychologist* or epileptologist* or provider* or physician*) NEAR/3 (attitude* or perception* or opinion* or view* or perspective* or understand* or belief* or communication or agreement or diagnosis or diagnoses or approach* or preference*)) AND ((Depersonalization or Malingering) OR ((Conversion or Dissociative or Factitious or

Psychophysiologic or Somatoform) NEAR/2 (Disorder*)) OR ((Conversion or Dissociative or Factitious or Psychophysiologic or Somatoform) NEAR/2 (Disorder*)) OR ((functional or psychogenic or hysteri* or pseudo or conversion) NEAR/2 ((conversion or factitious or psychophysiologic* or somatoform) NEAR/3 (disorder* or symptom*)) OR (Functional movement disorder* or Medically unexplained neurological symptom* or Psychogenic movement disorder* or functional neurological symptom*)) OR (((epilep* or seizure* or convuls*) OR (epilepsy or seizures)) AND ((Depersonalization or Malingering) OR ((Conversion or Dissociative or Factitious or Psychophysiologic or Somatoform) NEAR/2 (Disorder*)) OR TS= somati?ation)) OR ((functional or hysteri* or pseudo or unintended) NEAR/2 seizure*) OR ((nonepileptic or non-epileptic or psychogenic) NEAR/2 (attack* or seizure*)))

A total of 1117 publications were returned from this search. All titles were screened, and irrelevant items removed. Duplicates were also removed at this stage. Subsequently, abstracts were considered in more detail and further items were removed. In a final stage, full copies of these remaining publications were retrieved and read to consider their relevance to this review. These stages are presented in a flow chart in Figure 1.

Details of all inclusion and exclusion criteria can be seen in Table 1. Publications that did not differentiate between DS and functional neurological symptoms more generally were excluded. Opinion pieces that only related the views of clinician authors were excluded as such papers may only reflect the views of individuals rather than attempting to obtain a representative sample of a clinician group. The nature of the subject under study did not justify the exclusion of either qualitative or quantitative methodologies.

Table 1

*Details of inclusion and exclusion criteria*Inclusion criteria

1) Participants were clinicians of any professional background who encounter DS regularly or occasionally in their work.

2) Participants were asked to express an opinion regarding an aspect of DS diagnosis or treatment, or were asked to describe their experience of working with this client group

3) Study was published in English

4) An explicit qualitative or quantitative methodology was employed in the study

5) Studies was published in a peer-reviewed journal

Exclusion criteria

1) Studies that asked clinicians to express their opinions, experiences or treatment preferences regarding functional neurological symptoms, but did not differentiate DS from other forms of

functional neurological symptoms

2) Opinion piece articles that expressed the views of a clinician author or authors regarding DS, but did not attempt include data on clinician opinions from a representative sample of individuals

3) Case studies that only reported the views of individual therapists

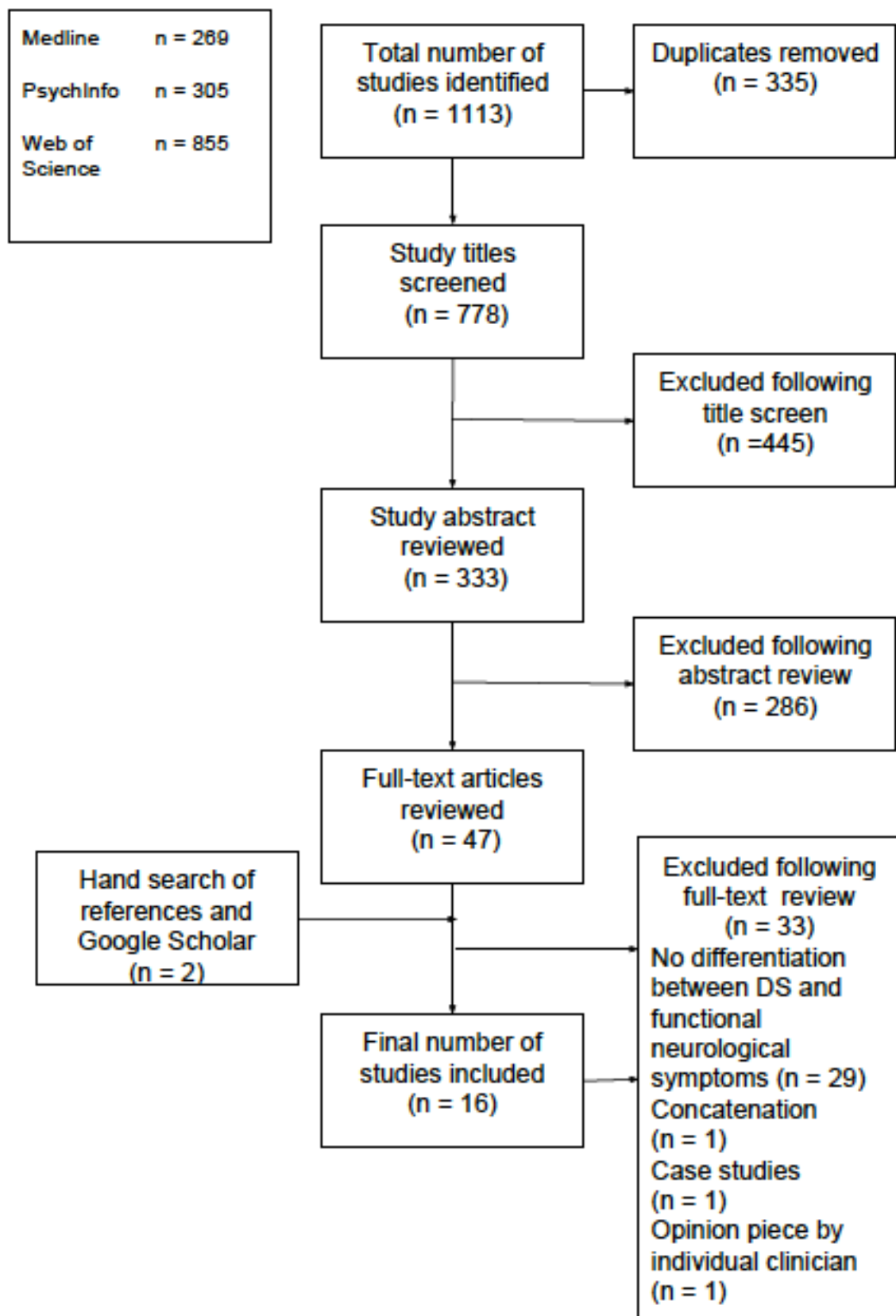


Figure 1. Search strategy flow chart

Literature Review

Description of included studies

Sixteen studies were identified as being relevant to this review. Of these, 15 of these were quantitative studies employing survey-based designs, and two were qualitative studies involving analysis of semi-structured interviews. Table 2 summarises details of the study aims, participants, response rates, and relevant findings of the identified studies. In view of the use of such methodologies, the Quality Assessment Tool for Studies with Diverse Designs (Appendix A) was employed to appraise the quality of included publications (Sirriyeh, Lawton, Gardner & Armitage, 2011). This tool has demonstrated good reliability and validity in the evaluation of qualitative and quantitative studies (Sirriyeh et al., 2011), and has been employed in the evaluation of survey-based research concerning clinicians' experience of providing interventions (e.g. Sheals, Tomobor, McNeill & Shahab, 2016). Details of this quality appraisal can be found in Appendix B.

The first half of this review is ordered in such a way that it follows an appropriate referral route for an individual who experiences DS: findings regarding the understanding and opinions of primary care physicians regarding DS and its treatment are considered first, followed by those of neurologists and psychiatrists, and finally those of psychological therapists. This is followed by a section focusing on clinicians' attitudes towards alternative conceptualisations of DS, and a final section considers evidence for stigmatising attitudes towards individuals with DS among clinicians.

Table 2

Summary of included studies

Author	Country	Aim	Participants and procedures	Response rate	Main findings
Aatti et al., 2016	France	To understand French psychiatrists level of knowledge and perceptions of DS, and to understand the relationship between psychiatrists' level of education regarding DS and their perceptions of the condition	A previously evaluated 38-item questionnaire regarding perceptions of DS, and a 13-item questionnaire regarding levels of DS knowledge were emailed through to French psychiatrists. A large number of psychiatrists responded (N=963). Inferential statistics were employed to determine relationships between psychiatrists' knowledge and levels of experience concerning DS and their perceptions and experiences of DS.	36%	Seventy-five percent of psychiatrists reported having had no training on DS, and 42% said that they had no experience of treating clients with DS. DS was perceived to be an impactful, chronic condition. Psychiatrists demonstrated a limited understanding of the condition. Greater levels of knowledge were found among those psychiatrists who had received training in DS. Those psychiatrists who had received training in DS reported having a significantly higher level of interest in the condition, and managed significantly more clients with the condition.
Asadi-Pooya, 2016	Iran	To investigate the perceptions of neurologists regarding DS: specifically their understanding of the typical symptoms of DS, best diagnostic practice and best treatment pathways	Neurologists (N=18) attending an annual neurology meeting were asked to complete an original survey with an unspecified number of items. Descriptive statistics employed to relate findings.	90%	The results of the questionnaire suggest that there was inconsistency in neurologists' views regarding the features that differentiate epileptic seizures and DS. Furthermore, only 50% of neurologists would routinely request EEG, and only 22% would routinely employ video-EEG. Sixty-seven percent would routinely refer to a psychologist or psychiatrist. Twenty-eight percent of neurologists reported always discontinuing anti-epileptic medication.
Harden et al., 2003	USA	To see whether psychiatrists and neurologists differ in their views on the diagnosis and management of DS	A brief questionnaire was given to neurologists (n=50) and psychiatrists (n=75) who were attending three neurology and psychiatry-related conferences. Inferential statistics were employed to compare the responses of these two groups.	99%	Significantly more neurologists considered EEG to be an accurate diagnostic method than psychiatrists. Within both groups, the majority of participants felt that best the best treatment of DS would 'depend on psychiatric diagnosis'. 64% of neurologists and 44% of psychiatrists felt that 'patients' own psychopathology interferes with treatment'. 32% of neurologists and 44% of psychiatrists thought that doctors 'dropped the ball'.

Jimenez et al., 2015	USA	To compare the preferences of different professional groups for either a biopsychosocial/3Ps approach or a Multiaxial or narrative approach in formulating DS	A vignette-based questionnaire emailed to clinicians working at an academic medical centre. Respondents included 'Non-psychiatry staff' (Epileptologists, epilepsy fellows, epilepsy-specialist nurses (n=30), Psychologists (n=20)) and 'Psychiatry staff' ((staff level psychiatrists (n=19); Psychiatry trainees (n=30)). Inferential statistics employed to compare Non-psychiatry staff views with those of psychiatry staff.	61%	The staff psychiatry group had a preference for the Narrative formulation approach, while the psychiatry trainee group had a slight preference for the multiaxial approach over the other two approaches. Both psychologists and epilepsy clinicians had a clear preference for biopsychosocial formulation. There was a highly significant preference for BPS/PPP formulation by nonpsychiatrists compared with psychiatrists
Jimenez et al., 2016	USA	To investigate whether healthcare providers prefer a biopsychosocial/3Ps approach to a Multiaxial or narrative approach in formulating DS	A vignette-based questionnaire emailed to Social worker psychotherapists (n=106) and counsellor psychotherapists (n=37) who were members of a regional social workers association or a regional counselling association. Inferential statistics employed to determine whether there was a significant preference for one of three formulation approaches.	9%	Psychotherapists had a significant preference for the biopsychosocial formulation approach over the multiaxial and narrative approaches to presenting this information. Qualitative reports suggest that this was due to its comparatively comprehensive nature, implied treatment targets and humanistic nature.
LaFrance et al., 2008	USA (+3.5% international respondents)	To improve understanding of what constitutes 'treatment as usual' for patients with DS	An original 20-item questionnaire emailed to professional members of an epilepsy society. Respondents included diverse clinicians (Epileptologists (n=209), Other neurologists (n=24), neuropsychologists (n=24), nurses (n=20), other (n=40)). Descriptive statistics employed to relate quantitative items and some qualitative responses to open questions reported.	18%	Respondents indicated that they felt that neurologists should follow-up with patients to address misgivings about the referral to psychology/psychiatry. They also indicated importance of 'nonjudgemental, compassionate & nonconfrontational' discussion of diagnosis. Family involvement was considered important. Some respondents acknowledged the potentially distressing implications of the diagnosis and the need to address the patient's life stressors.
Mayor et al., 2011	UK	To describe current management of DS and highlight differences in practice	An original 34-item questionnaire emailed to members of the UK Chapter of the International League Against Epilepsy and the Association of British neurologists. Respondents included diverse clinicians (Consultants (n=83); Speciality registrars (n=18); Nurses and specialist nurses (N=26); Clinical psychologists (n=3); all predominantly working in neurology (66.4%), pediatrics or neuropediatrics (12%) or epileptology (5.2%)). Descriptive statistics employed to relate findings.	5.8%	Ninety-three percent of respondents endorsed psychological treatment as treatment of choice, while only 35% were able to refer all their patients and 15% were unable to refer any patients. Clinicians referred more ambiguous diagnostic terms that did not favour a psychological etiology. 'Nonepileptic attacks' was most commonly used at diagnosis, followed by 'nonepileptic attack disorder' and 'nonepileptic seizures'.

McMillan et al., 2014	US	To describe the perceptions of clinicians working with DS within the context of a specialist epilepsy service line for military veterans	Semi-structured telephone-based interviews lasting 'an average of 15-20' minutes were conducted with 74 clinicians who had responded to an email request sent to 750 people working in such services. Participants included neurologists (n=48), nurses (n=13) and others (n=13). Grounded theory was employed to analyse the resulting transcripts.	9.8%	Two overarching themes of 'frustration' and 'hope' emerged. Subthemes under 'frustration' included: 1) frustrations from the nature of the diagnosis 2) Frustrations from perceived characteristics of clients with DS, 3) The limitations of treatment options 4) Issues with the specific veterans' health service. Under 'hope', participants reported positive experiences of working with the client, hopefulness regarding progress in treatment of the condition and experiences of successful multidisciplinary working.
O'Sullivan et al., 2006	Republic of Ireland	To explore the level of understanding of DS diagnosis, opinions on the diagnosis, and the role played by GPs in the management of DS	An original 16-item questionnaire emailed to purposively identified GPs who had individuals with DS under their care (N=23). Descriptive statistics employed to relate quantitative items, no formal qualitative analysis of open questions reported.	88%	GPs responses suggested limited confidence in diagnosis understanding, some disagreement with application of the diagnosis, low opinion of the value of psychology and psychiatry in treating the condition and varied opinion regarding the role of GPs in ongoing management of DS
Pliplys et al., 2014	USA	To investigate factors that relate to the clinicians' decisions to discontinue epileptic medication in patients with DS	An original 23-item questionnaire emailed to members of the American Epilepsy Society and members of the Child Neurology Society (Neurologists (n=213); Nurses (n=23)). Inferential statistics employed to identify factors that might influence a decision to discontinue antiepileptic medication.	Not calculable, likely <10%	96.2% of respondents were likely to discontinue epileptic drugs after diagnosis of dissociative seizures, though requests from patients or fear of error could influence this decision in some cases. Having sufficient knowledge regarding the diagnosis was also associated with the decision to discontinue antiepileptic medication, as was the availability of psychiatric treatment.
Quinn et al., 2010	Australia	To explore the idea that a clear assessment of client history, comorbidity and 'skill development' helps to develop 'clarity in treatment'	Participants were respondents to advertisements at unspecified 'annual conferences' and placed in four professional newsletters. Snowball sampling was also employed. Respondents (N=8) included psychiatrists, psychologists and one nurse who practiced psychotherapy. Details of their DS clients were obtained. Unstructured interviews lasting 1-2 hours were conducted and analysed using grounded theory.	Not reported	The analysis suggested that participants considered DS were one symptom (among others) that arose as a response to trauma and 'invalidation' in formative relationships. Therapists suggested that they arose as a result of verbal communication being prohibited, and nonverbal communication being encouraged. Such seizures were thus viewed as a means of communication, or as a means of managing intolerable situations or emotions. Therapists reported that therapy could be transformative for both clients and themselves.

Sahaya et al., 2012	USA	To assess the opinion of health care providers towards DS and to identify areas which need attention to improve care	An original 7-item questionnaire was administered by 'approaching' healthcare professionals working at a single university hospital. Respondents included 'Primary care healthcare providers' (n=49), Neurologists (n=16) and inpatient nurses (n=39). Descriptive statistics were employed to relate findings. Comparisons made between groups, though no inferential statistics employed.	34%	Diversity in preferred diagnostic terms, including regular use of term 'Pseudo seizure'. 'Fake seizure' preferred by 5 providers. Two-thirds of providers felt that EEG was important in diagnosis. Psychiatry most preferred speciality to manage DS. Low confidence among primary care providers in working with people with this diagnosis
Shneker & Elliot, 2008	USA	To gain an understanding of attitudes and beliefs among non-neurologist physicians, who are likely to encounter DS in their practice'	An original 17-item questionnaire emailed to individuals listed on a Medical Centre database and a research foundation database. Respondents included Family medicine speciality doctors (n=49), Internal medicine speciality doctors (n=63) and Emergency medicine speciality doctors (n=47). Inferential statistics were employed to compare responses of different clinician groups.	22%	Findings indicate some attitudes that are consistent with current understanding, but also many misconceptions that are inconsistent with best practice. Evidence of a lack of thoroughness in diagnosis. 39% felt DS were voluntarily induced, 85% use 'pseudoseizures'. Various differences observed between specialities including significantly greater confidence in diagnosis among Emergency medicine specialists, and a significantly higher belief that DS are voluntarily induced among this group.
Whitehead & Reuber, 2012	UK	To compare the illness perceptions of neurologists and psychiatrists in relation to epilepsy and DS	A previously evaluated 38-item questionnaire was emailed to members of the UK Chapter of the International League Against Epilepsy and the British Neuropsychiatry association. Respondents included Neurologists (n=45) and Psychiatrists (n=40). Inferential statistics were employed to compare the responses of these two groups.	Not calculable, likely <10%	Both groups thought that patients with DS had greater personal control over their condition than patients with epilepsy, and that DS was a more cyclical condition than epilepsy. Both groups of professed a greater understanding of epilepsy than DS. Psychiatrists alone believed epilepsy to be more chronic than DS. Psychiatrists felt that epilepsy had less of an emotional impact on patients and were more likely to endorse psychological causes for epilepsy compared to neurologists. Psychiatrists felt that DS had less negative consequences and were more likely to endorse nonpsychological causes for DS when compared to neurologists.
Whitehead et al., 2013	UK	To compare the illness perception of patients with epilepsy and patients with DS with each other and with those of neurologists to both disorders	A previously evaluated 38-item questionnaire was emailed to members of the UK Chapter of the International League Against Epilepsy. The same questionnaire was administered to individuals with DS (n=40) and individuals with epilepsy (n=34) who had were approached prior to attending neurology appointments at a single hospital. Inferential statistics were employed to compare neurologists' responses (n=45) with those of both client groups.	Not explicitly reported, Not calculable, likely <10%	Neurologists significantly more likely to endorse psychological causes and less likely to endorse non-psychological causes for DS than patients with DS. Conversely, neurologists significantly less likely to endorse psychological causes for epilepsy than patients with epilepsy

Worsely et al., 2011	UK	To describe the illness perceptions of two groups of health care professionals and contrast the illness perceptions of the two individual groups'	A previously evaluated 38-item questionnaire was distributed to staff working in a neurology inpatient setting, a neurology outpatient setting and a hospital emergency department. Respondent groups included 'Neurology ward staff' (n=31) (neurophysiology technicians (n=20), nurses (n=8), health care assistants (n=3)) and 'Emergency Care staff' (n=30) (emergency department nurses (n=27), ambulance crew members (n=3)). Inferential statistics were employed to compare the responses of these two groups.	Not reported	1) Both groups rated DS as less chronic and more within the control of the patient. Both groups reported a better understanding of epilepsy than DS and both endorsed more psychological causes for DS than epilepsy. Only neurology ward staff thought there were more nonpsychological causes for epilepsy than psychological causes 2) Neurology ward staff perceived DS as more chronic than emergency ward staff. Neurology ward staff felt they had a greater understanding of both epilepsy and DS. Emergency staff attributed more nonpsychological causes for DS than neurology ward staff. [see paper for more]
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Views of primary care staff and contrast with epilepsy specialists

Primary care professionals are the first point of contact in healthcare services for individuals seeking support for DS. Moreover, the ongoing involvement of referring clinicians may be of value in order to reduce the possibility of such individuals feeling 'abandoned into the sole care of a psychiatrist' (Shen, Bowman & Markand, 1990 p. 758). The literature search yielded three papers that considered the views and opinions of hospital-based primary care professionals, and two papers that included the perspective of GPs.

O'Sullivan, Sweeney and McNamara (2006) surveyed purposively identified GPs practicing in the Republic of Ireland to gain greater understanding of their understanding of DS and their role in managing individuals under their care who had received this diagnosis. The 23 GPs who responded to their brief, unvalidated questionnaire expressed a limited understanding of DS, reporting a mean confidence level of 5.7/10 (SD = 2.3). The majority (65%) of respondents indicated that they did not believe that psychiatric or psychological interventions for DS were useful for their clients, and a significant proportion (35%) disputed the neurologist's diagnosis of DS. In a US-based survey, a self-selected group of family practice physicians indicated a similarly low confidence rating in managing DS, reporting a mean score of 4.94/10 (SD = 2.11) (Shneker & Elliot, 2008). The authors also reported a number of misconceptions among these physicians regarding DS. In particular, they expressed opinions on diagnosis and treatment that are inconsistent with best practice (LaFrance, Reuber & Goldstein, 2013), with a majority holding the view that video-EEG is not necessary for diagnosis. Similarly low confidence levels and misconceptions were reported by Internal Medicine and Emergency Medicine physicians (Shneker & Elliot, 2008).

In some cases, researchers sought to compare the understanding and opinions of primary care staff with those of epilepsy specialists. In comparing the views of UK-based emergency care staff with those of neurology ward staff, Worsely, Whitehead, Kandler and Reuber (2011) distributed the 'Illness Perception Questionnaire-Revised' (IPQ-R) (a scale with good internal consistency and test-retest reliability that was originally designed to assess the illness perceptions of individuals with chronic health conditions) to staff working in a neurology setting or an emergency department. Emergency care professionals reported a significantly lower level of understanding of the condition, and were significantly less likely to attribute DS 'mainly' or 'entirely' to psychological causes. While emergency care staff did not differ in their view on the impact of DS relative to neurology staff, they considered DS as a significantly less chronic condition. Similarly, a US-based survey found that when self-selected primary care clinicians working in a university hospital were asked to rate their level of comfort in 'dealing with a patient' with DS on a scale of 0-10, they returned lower scores than neurologists ($M = 7.71$, $SD = 1.68$ and $M = 4.34$, $SD = 2.50$ respectively) (Sahaya, Dholakia, Lardizabal & Sahota, 2012). However, inferential statistics were not employed to determine whether this difference was significant.

Differences between primary care staff and neurology-specialists can also be observed in the contrasting terminology employed by these groups in referring to DS. Terminology among US-based epilepsy specialists has been reported to be relatively standardized, with 'Non-epileptic seizures' being much the preferred term among responding professionals affiliated with the American Epilepsy Society (LaFrance, Rusch & Machan, 2007). Mayor, Smith and Reuber (2011) reported that terminology among UK-based epilepsy-specialists was more diverse, with 'non-epileptic attacks'

and 'non-epileptic seizures' being similarly popular. Nevertheless, in both cases such terminology is considered to be current and inoffensive (Brigo et al., 2015), and few participants endorsed the problematic term 'pseudoseizures'. In contrast, 'pseudoseizure' was approved by 85% of primary care and emergency care physicians (Shneker & Elliot, 2008), and was the preferred term among non-specialist inpatient nurses (Sahaya et al., 2012). Nevertheless, it should be noted that in this later study, the proportion of primary care physicians endorsing this term (26%) was much smaller than that reported by Shneker and Elliot (2008).

Commonalities and differences in the views of neurologists and psychiatrists

Neurologists and psychiatrists reported some similar views regarding their understanding and preferences concerning DS and their treatment, but also some areas of divergence. With regards to the diagnosis of DS, Harden, Burgut and Kanner (2003) reported that neurologists and psychiatrists had significantly differing views regarding the accuracy of video-EEG diagnosis. In a survey of psychiatrists and neurologists attending neurology and psychiatry conferences, 70% of responding neurologists compared with 18% of psychiatrists believed that video-EEG is an accurate diagnostic method 'most of the time' ($p < 0.001$). However, more recent research suggests that psychiatrists may have a more favourable view of the validity of video-EEG diagnosis. In an email-based survey of French psychiatrists, Aatti and colleagues (2016) reported that 79% of psychiatrists considered video-EEG to be the 'gold standard diagnostic test'. The results of this survey should be given weight due to the large number of respondents (963) and relatively high response rate (36%). A similarly high level of confidence in the accuracy of video-EEG diagnosis among neurologists was observed in a survey of members of the American Epilepsy Society

(Plioplys et al., 2014). Ninety-eight percent of respondents to this survey (90.2% of which were neurologists) reported high or moderate confidence in the reliability of video-EEG diagnosis. This figure should be treated with caution due to the risk of selection bias: the survey had a response rate of 5.5%.

The available literature suggested that neurologists and psychiatrists have some differences of opinion regarding the etiology of DS. Employing a similar methodology to Worsely and colleagues (2011), Whitehead and Reuber (2012) compared the relative perceptions of neurologists and psychiatrists regarding both epilepsy and DS. While responses to the IPQ-R indicated that all responding neurologists and psychiatrists considered DS to be 'mainly' or 'entirely' of psychological etiology, neurologists were significantly more likely than psychiatrists to attribute DS 'entirely' to psychological causes ($p = 0.011$). Both neurologists and psychiatrists cited 'emotional abuse' as one of the three most important causes of DS. However, for neurologists the other two chief causes were 'patient's personality' and 'physical abuse', while psychiatrists cited 'stress or worry' and 'sexual abuse'. Employing the same data set to compare these neurologists' views with those of individuals with DS, Whitehead, Kandler and Reuber (2013) reported that neurologists were significantly more likely to endorse psychological causes for DS ($p < 0.001$).

Five surveys considered the view of neurologists and psychiatrists regarding the efficacy of available treatment options. Considering the views of UK-based psychiatrists and neurologists, two studies employed the 'Treatment Control' subscale of the IPQ-R (a subscale that rated clinicians' perceptions of the effectiveness of available treatment on a scale of 5-25) (Whitehead & Reuber, 2012; Whitehead et al., 2013). Psychiatrists and neurologists did not differ significantly on this subscale,

returning a mean score of 20 and 19 respectively. Individuals with DS reported a significantly lower score than neurologists ($M = 18$). Regarding specific treatment options, Harden et al., (2003) reported that the majority of responding American neurologists and psychiatrists felt that the best course of treatment was dependent on the nature of the psychiatric diagnosis (60% and 66% respectively). Despite being the most popular choice of treatment, only 16% of neurologists and 22% of psychiatrists recommended treatment with psychotherapy. In contrast, a later survey found that a significant majority (80.7%) of responding American epilepsy specialists (predominantly neurologists) reported that psychotherapy is an effective treatment for DS, and many also endorsed psychoeducation as a useful intervention (71.7%) (LaFrance et al., 2008).

Still greater support for the use of psychological intervention amongst neurologists was reported in a survey of the UK Chapter of the International League Against Epilepsy and the Association of British neurologists, with 93% of responding epilepsy specialists (65% neurologists) reporting that they believed psychotherapy to be the best mode of treatment for DS, and 100% reporting that they either refer or recommend clients to psychological services (Mayor et al., 2011). Selection bias may have been present, as this survey had a low response rate of 5.8%. Finally, a small ($N=20$) survey of Iranian neurologists found that the majority of respondents (67%) chose to refer their clients to a psychologist or psychiatrist following a diagnosis of DS (Asadi-Pooya, 2016). Overall, the evidence from these papers suggested that in the past neurologists and psychiatrists may have viewed DS as a condition that was not amenable to treatment by any means, but that they have developed a more optimistic view, with psychological therapy being the treatment of choice.

The available literature did not suggest that neurologists and psychiatrists differ significantly in their self-reported levels of understanding regarding DS. In responding to the 'illness coherence' subscale of the IPQ-R (a subscale that indicated their level of understanding of the condition on a scale of 5-25), Whitehead and Reuber (2012) reported that participating neurologists and psychiatrists returned the same mean score and interquartile range ($M = 19 (4)$). Inferential statistics indicated that both groups reported a significantly higher level of understanding of epilepsy than DS. In comparing levels of understanding in neurologists and individuals with DS, Whitehead and colleagues (2013) reported significantly higher levels of understanding amongst neurologists, with these groups scoring 20 and 14 respectively on this subscale. A survey of members of the American Epilepsy Society also indicated high levels of understanding amongst epilepsy specialists, with 86% of respondents (primarily neurologists) reporting sufficient knowledge to diagnose the disorder, and 68% reporting sufficient knowledge to treat the disorder (Sahaya et al., 2012). Taking these findings together, it appears that both UK and US-based neurologists and psychiatrists feel that they have a moderate degree of understanding of DS, but that many still feel inadequately equipped to effectively treat the condition.

Views and experiences of psychological therapists

Despite the emphasis placed on the role of psychotherapeutic interventions by non-therapist clinicians (Mayor et al., 2011), only three studies considered the views and experiences of psychological therapists treating DS. Two of these studies (Jimenez, Bautista, Tesar & Fan, 2015; Jimenez et al., 2016) considered therapists' views regarding a highly circumscribed domain (formulation approach) and are considered in the following subsection.

Employing a grounded theory methodology, Quinn, Schofield and Middleton (2010) analysed semi-structured interviews with Australian psychotherapists who had treated at least one DS client within the past five years. Participants were eight therapists who responded to advertisements displayed at annual conferences and in professional newsletters (no estimates of recruitment rate were provided). Regarding therapist views on the etiology of DS, emergent themes suggested that participants considered DS to arise as a result of the 'proscription of verbal communication' and the 'prescription of nonverbal communication'. Therapists maintained that their clients had learnt from an early age to avoid verbal communication of their experiences of trauma, and instead were encouraged to adopt nonverbal means to express distress. Therapists viewed DS as one method (among others) of nonverbal communication. In addition, therapists viewed DS as a means of escaping memories of past trauma or present difficulties.

With regards to therapists' confidence level in working with clients with DS, the emergent themes reported in this study suggested that therapists did not feel that they had a good understanding of the condition (Quinn et al., 2010). Participants described being 'absolutely ignorant of what they were working with' (p. 116) and that they 'wrestled with enigmatic patients' (p. 117). Therapists also reported that it could be a challenge to develop trusting relationships with their clients due to their past experience of abusive relationships. The authors concluded that therapists were typically 'poorly prepared' for working with clients with DS. They added that such work is always likely to be challenging due to the complex nature of this client group, and therapists require 'considerable willingness to tolerate their own uncertainty and confusion' (p. 120).

This study exhibited some methodological strengths. The authors provided detailed information regarding relevant demographic information including gender, age, experience level and professional background. Additional details were provided regarding the demographics and comorbidities of clients treated. A clear description of theoretical orientation and the analytic process was provided, including use of multiple researchers in the analytic process, authors adopting different perspectives, and consideration of reflexivity. There was some suggestion that the therapists' theoretical orientation was primarily psychodynamic: referenced clients were seen for 2-13 years, therapists placed particular emphasis on early relationships and early life trauma, and stressed the importance of their own emotional reactions to their clients during sessions. Their theoretical approach was not explicitly described. The psychological model adopted by therapists (e.g. cognitive-behavioural or psychodynamic) may have had considerable influence on their opinion of issues such as etiology. The very limited sample size ($N = 8$), the inclusion of researchers as participants, and the lack of detailed recruitment data significantly reduces the extent to which this sample may be considered representative of the broadly defined target population of 'therapists'.

Clinician views on alternative conceptualisation and communication of DS

In view of the multiple factors that are believed to contribute to the causation of DS, two papers considered clinicians' attitudes towards different approaches to the formulation and communication of the condition. Jimenez and colleagues (2015) distributed an electronic survey to four groups of epilepsy-specialist clinicians based at a single US-based medical centre: epilepsy clinicians (epileptologists, epilepsy

fellows and epilepsy nurses), staff level psychiatrists, trainee psychiatrists and psychologists. Participants were provided with a case vignette and asked to indicate their order of preference for three different approaches to describing and explaining the difficulties presented in the vignette. One approach was multiaxial diagnosis, in which five different domains are considered: clinical disorders, personality disorders, medical disorders, psychosocial factors and global assessment of functioning. A second approach was a narrative approach in which a brief narrative of the client's difficulties is provided in prose. The final option was a biopsychosocial formulation in which predisposing, perpetuating and precipitating biological, psychological and social factors were summarised in grid format.

Jimenez and colleagues (2015) reported that the narrative approach was favoured by 50% of staff psychiatrists. Psychiatry trainees were more divided, with 41% preferring a multiaxial approach and 35% supporting the narrative approach. Both epilepsy clinicians (62%) and psychologists (78%) favoured biopsychosocial formulation. Inferential statistics indicated that significantly more non-psychiatrist clinicians preferred the biopsychosocial approach ($p < 0.001$). In applying the same methodology to compare the preferences of 'social work psychotherapists' and counsellors based in a single US state, Jimenez and colleagues (2016) found that the majority of both groups (75% and 62% respectively) favoured the biopsychosocial approach. This preference was found to be statistically significant ($p < 0.001$).

Pejorative views expressed by clinicians

In eight of the papers identified in this search, the questions asked of clinicians served to elicit some responses that could be seen as pejorative or patient blaming. The use of potentially stigmatising terminology for the condition was one example of this. As mentioned previously, several studies found that the term 'pseudoseizure'

remained in use among a primary care clinicians (Shneker & Elliot, 2008) and inpatient nurses (Sahaya et al., 2012). Research suggests that this term has offensive connotations for clients with DS, and may be associated with feigning and secondary gain (Stone et al., 2003). In one survey, four nurses endorsed the particularly pejorative term 'fake seizure' for DS (Sahaya et al., 2012).

Four papers provided evidence that some clinicians believe individuals with DS have particular personality traits or exhibit particular behaviours that serve to sustain their difficulties. Harden et al., (2003) found that 46% of US-based psychiatrists and 64% of neurologists who responded to their survey believed that 'patients' own psychopathology interferes with treatment', and that this was the main reason for therapeutic failure. Similarly, Worsely et al. (2011) reported that UK-based emergency care clinicians who responded to their survey cited 'patients' own behaviour' as one of the top three causes of DS. A survey of UK-based neurologists found that 13% of respondents considered 'patient's personality' as an important cause of DS (Whitehead et al., 2013). Similarly, LaFrance et al. (2008) found a small proportion of responding neurologists (5.4%) advised their clients that their DS may be the result of 'purposive behaviour'.

Three papers provided a clear indication that some clinicians believe that individuals with DS may be faking their symptoms. Shneker and Elliot (2008) reported that 38% of primary care and emergency physicians surveyed agreed with the statement that 'Most pseudoseizures and voluntarily induced (patients are fakers)', with this attitude being present in the majority of emergency medicine physicians (53%). Seventy-two percent of all respondents also felt that clients refuse to accept the diagnosis of DS. Particularly disturbing comments regarding malingering were reported by Worsely and colleagues (2011), who informally observed participants in

their study to make comments such as 'patients were time wasters', 'fakers', or 'should be shot' (p. 672).

Similarly, in a qualitative investigation of healthcare professionals working within the US Veterans Health Association, McMillan and colleagues (2014) reported a clear indication that treating clinicians sometimes perceived their clients to be faking their DS. Employing an analytical approach that was 'derived' from grounded theory, the researchers analysed transcripts of brief (15-20 minute) semi-structured interviews with 79 responding professionals (of which 65% were neurologists). Within the overarching theme of 'Frustration', respondents described perceiving some of their clients' symptoms as 'too convenient' and that they might be 'faking it' (p. 277). Clinicians described how, in some cases, such malingering was motivated by secondary gain – that they were 'gaming the system' and had 'little motivation to engage' due to the potential loss of disability benefits (p.278). Other potentially stigmatising attitudes were reported, including a perception that some clients with DS were 'beyond help' and 'hopeless (p 277). The findings of this study should be given weight, as it benefitted from a clearly detailed process of qualitative analysis that was conducted by multiple researchers of differing professional backgrounds. Furthermore, additional independent analysis was conducted by researchers who were blinded to client identities and existing coding.

Progressive views expressed by clinicians

While there was evidence of pejorative views among clinicians regarding individuals with DS, there was also evidence that some clinicians held compassionate views and acknowledged the limitations of treatment. As noted previously, Harden et al. (2003) found views amongst neurologists that might be considered patient-

blaming. However, they also found that 32% of responding neurologists held the view that the primary reason for treatment failure was not due to the shortcomings of their clients, but was instead due to physicians “dropping the ball”. More compassionate views among responding epilepsy specialists were also reported by LaFrance et al. (2008). Following an analysis of open-ended questions by ‘qualitative assessment’, the researchers reported that 90% of respondents emphasized a ‘nonjudgemental, compassionate and nonconfrontational discussion of the diagnosis’.

A considerable degree of compassion and self-reflection regarding work with clients with DS was expressed by psychotherapists interviewed by Quinn et al. (2010). Therapists recognised the limits of their own understanding, and were aware of the impact that this may have been having on their own reactions: ‘They wrestled with... their own ‘internal states of cognitive and emotional dissonance) (p. 117). Therapists also acknowledged the likely impact of adverse life experiences on such clients’ ability to trust professionals: ‘I can say to a person, ‘you can trust me’. It means nothing if you have been abused’ (p. 117). Therapists also stressed the need for collaborative working, and the value of reaching a shared understanding with their clients (Quinn et al., 2010).

While, as previously detailed, McMillan and colleagues (2014) reported pejorative and unconstructive views among clinicians treating DS, there was also evidence of compassion and humility. In some cases, clinicians recognised the role that they may be playing in perpetuating stigma by harbouring unsubstantiated assumptions regarding malingering. Moreover, participants reported that they considered working with such clients was a ‘good use of my time’ (p. 278) and that they would provide additional follow-up meetings in order to ensure their welfare. Other participants expressed a belief in the importance of validating the experiences

of individuals with DS, and also stressed the importance treating them with 'respect, understanding and empathy' (p. 279). An overarching emergent theme of 'Hope' among interviewees was reported, which included a belief among some clinicians that the diagnosis of DS is being 'taken seriously' and 'has a little more respect' due to better education of staff (p. 279). The generalisability of these findings may be somewhat limited due to the specific context in which the participants worked (a health service for veterans of the US army). Nevertheless, such reports provide evidence that there is thoughtfulness and compassion among some clinicians working to treat individuals with DS.

Methodological issues across survey-based studies

There were some common methodological issues across the survey-based studies that meant that the reported findings should be treated with some caution. Eight studies relied on an internet-survey based method of data collection (Aatti et al., 2016; Jimenez et al., 2016; LaFrance et al., 2008; Mayor et al., 2011; McMillan et al., 2015; Plioplys, 2014; Whitehead et al., 2011; Whitehead & Reuber, 2012). While this approach enabled researchers to obtain a larger number of participants than those that employed opportunity sampling, such a methodology introduces a significant risk of selection bias. Typically, emails were sent to individuals whose email addresses were on large databases of clinicians, and fewer than 10% of those approached would respond (e.g. Mayor et al., 2011). In such cases, respondents may not be representative of the target population – it may be that they have a particular interest in the subject area, or represent a generally more open and motivated group of individuals. One group of researchers suggested that their email-based methodology may have discriminated against more elderly or visually impaired clinicians who

might not have accessed the survey (LaFrance et al., 2008). In cases where selection bias was likely, due to low response rates, it may have been beneficial for researchers to have obtained demographic data regarding the target population, and to have compared this with the demographic data of the sample they obtained. No such analysis was evident in these surveys. Nevertheless, it should be noted that one email-based study obtained a considerably higher response rate (36%), and acquired a sample that represented 10% of all French psychiatrists (Aatti et al., 2016). This survey may have benefitted from the use of multiple recruitment strategies including use of personal communications and indirect recruitment through multiple professional associations.

A further complicating factor was identified in some email-based surveys (Mayor et al., 2011; Plioplys, 2014; Whitehead & Reuber, 2012; Whitehead et al., 2013). It was not possible to calculate true response rates due to the use of overlapping email databases. For example, Whitehead and Reuber (2012) acknowledged that some members of the United Kingdom Chapter of the International League Against Epilepsy were likely to be members of the British Neuropsychiatry Association. Hence the true number of individuals approached in the study was obscured. In studies where overlapping memberships were an issue, the methodology may have benefitted from an analysis of databases to identify duplicates.

All of the papers identified in this search relied on participant self-reports of their attitudes and opinions. It should be noted that self-report regarding issues that may be taboo among professionals (such as stigmatising views of service users) may be subject to an inclination on the part of participants to respond in a way that is socially desirable (Krumpal, 2013). This may have led respondents to both survey-

based and interview-based studies to express views of DS they considered to be the 'professionally correct' view, rather than report their genuine opinion. Evidence for such a bias was observed by Worsely and colleagues (2011), who reported that 'Emergency care staff made some strong comments about patients with PNES that are not really reflected by the assessment tools here' (p. 672).

There was inconsistent use of questionnaire validation and quality assessment across surveys. In some cases, authors provided a clear rationale for the questionnaire employed, and referenced evidence of internal consistency and test-retest reliability – notably, this was the case with studies that employed the IPQ-R (Aatti et al., 2016; Whitehead et al., 2011; Whitehead & Reuber, 2012; Worsely et al., 2011). In other cases, use of questionnaires without demonstrated reliability and consistency were reported; but evidence of prior use, piloting or expert review demonstrated a consideration of questionnaire validity (LaFrance et al., 2008; Jimenez et al., 2016). A number of researchers provided no such evidence that they had assessed the reliability or validity of their original questionnaires (Asadi-Pooya, 2016; Harden et al., 2003; Mayor et al., 2011; O'Sullivan et al., 2006; Plioplys et al., 2014; Sahaya et al., 2012; Shneker & Elliot, 2008). In one case, a clear issue with questionnaire design was noted: Shneker and Elliot (2008) included the question 'Is the term 'pseudoseizure' appropriate to use?', while employing the term 'pseudoseizure' throughout their questionnaire (such use may have implied its acceptability). Overall, the use of multiple original, unvalidated questionnaires in this field limits the confidence with which conclusions may be drawn regarding clinician opinions regarding DS, and prevents confident comparisons of findings across studies.

Finally, it should be noted that across all survey-based and also across both interview-based papers, there was no indication of service-user involvement in the

study design. This was a lost opportunity to consider the views of individuals with DS regarding the research that they feel is pertinent to their needs and interests.

Discussion

The aim of this review was to ascertain and evaluate the available evidence concerning the understanding and opinions of different clinicians concerning dissociative seizures. A further aim was to gain insights into clinicians' views concerning individuals with this condition, and their experience of working with such individuals.

The majority of studies identified in this literature search were survey-based and exhibited methodological issues (such as response bias and use of unvalidated questionnaires) that limited the validity and generalisability of their findings. Few studies employed a qualitative methodology, and the conclusions that could be drawn from those studies that did employ such a methodology were limited due either to a very small sample size (Quinn et al., 2010) or the unusual nature of the setting within which participants practiced (McMillan et al., 2014).

Despite these methodological limitations, some tentative conclusions may be drawn from the available literature. Firstly, it appeared that many participating clinicians did not have a good understanding of DS, and did not feel confident in their ability to help people with the condition. In both the US and the UK, primary care clinicians working in both general practices and hospital settings indicated a low level of understanding of the condition, and did not necessarily feel that they are equipped to help people with DS. Moreover, a skepticism regarding the ability of specialist services to intervene effectively in DS was apparent. As may be expected, neurologists and psychiatrists reported a higher level of understanding of the

condition compared with primary care staff. Nevertheless, some of these specialists reported having insufficient knowledge to effectively treat DS, and were observed to disagree on some fundamental aspects of the condition (particularly regarding etiology).

Secondly, while there was some evidence of positive, compassionate and reflective attitudes among clinicians involved in the treatment of DS, pejorative and client-blaming views were clearly present. The tendency among some clinicians to assume that clients may be faking their symptoms in order to fulfill an ulterior motive is consistent with the reported experiences of such clients (Robson & Lian, 2017). Such attitudes appeared to be particularly prevalent among non-specialist clinicians (Shneker & Elliot, 2008; Worsely et al., 2011), suggesting that such views may arise as a result of insufficient experience or inadequate training. Nevertheless, client-blaming and assumptions of malingering were also present among some neurologists and psychiatrists (Harden et al., 2003; McMillan et al., 2014; Whitehead et al., 2013). The presence of stigmatising attitudes across various stages of the care pathway for DS may be a significant factor in perpetuating the sense of stigma and neglect reported by individuals with the condition (Dickinson et al., 2010; Rawlings et al., 2017; Wang et al., 2017).

It is possible that these stigmatising views may arise in clinicians as a means of managing a sense of powerlessness and inadequacy regarding their ability to help individuals with DS. McMillan and colleagues (2014) identified 'frustration' as a key theme of their interviews with neurologists and other health professionals – such frustration appeared to relate in part to the perception that there are 'few good options' regarding treatment of condition (p. 278). The fact that DS is a complex and under-researched condition (Reuber & Brown, 2017) with a limited evidence-base for

effective treatment (Martlew, Pulman & Marson, 2014), and a lack of clinical consensus across professional groups (e.g. Worsely et al., 2011; Whitehead & Reuber, 2012) suggests that even highly specialist clinicians may feel ignorant and ineffective in their work with this client group.

It has been suggested that neurologists involved in the care of people with DS may sometimes feel that their medical authority is under threat in interactions with DS sufferers (Monzoni et al., 2011). This may be the case across professional groups: clinicians may experience feelings of inadequacy and impotence when confronted with a condition that they do not fully understand. This may be incompatible with their self-concept as competent clinicians. The Freudian concept of 'projection' may be relevant here: in order to defend against these intolerable feelings, clinicians may seek to locate attributes of deficiency in individuals with the condition rather than in themselves (Freud, 1966). In view of evidence regarding the association between client internalised stigma and perceived stigma in healthcare providers (Wang et al., 2017), it is also possible that individuals with DS may take on a more negative self-conception through identification with these projected attributes. This is consistent with the psychoanalytic concept of projective identification: that the recipient of a projection may indeed be led to adopt the attributes that have been projected (Laing, 1961).

Strengths and Limitations

This review condenses and contrasts an important body of literature concerning the views and experiences of clinicians involved in the treatment of a complex and challenging condition, but has some notable limitations. Due to the limited amount of publications identified, several older articles (e.g. Harden et al.,

2003) were not included that may not represent the views and experiences of current professionals. Some tentative evidence suggested clinicians' views had developed over time, which may represent useful progress. More recent surveys found primary care clinicians employed more appropriate terminology, using the potentially offensive term 'pseudoseizures' less frequently (e.g. Shneker & Elliot, 2008; Sahaya et al., 2012). Among neurologists and psychiatrists, there was evidence of increased confidence and clinical consensus regarding the use of video-EEG in diagnosis (Harden et al., 2003; Aatti et al., 2016; Plioplys et al., 2014). In the domain of treatment, there was evidence that neurologists had developed greater confidence in the utility of psychological interventions over time (Harden et al., 2003; LaFrance et al., 2008; Mayor et al., 2011). Although further progress is needed, such developments indicate that more sensitive, hopeful and consistent care is now available to those with DS.

The identified literature included an over-representation of US and UK-based samples. Only three publications reported findings from countries where English is not the first language. Evidence suggests significant differences in the conceptualisation of functional neurological symptoms across cultures (Kendall et al., 2012). The findings presented here may be culturally specific, not reflecting the views and experiences of clinicians working in non-Western, non-English speaking countries.

Publications considering clinician experiences of working with the superordinate diagnostic category of functional neurological disorders were excluded: this narrower scope was necessary to produce a focused and coherent review. However, useful insights may have been gained from including articles considering professionals' views of this broader category. Notably, qualitative methodologies

have been effectively employed to gain insight into the experiences of neurologists and psychiatrists treating functional neurological disorder (Kanaan, Armstrong & Wessely, 2009; 2016).

Clinical Implications

The literature presented here provided evidence that some staff members involved in the treatment of DS have misconceptions regarding the diagnosis and its treatment (e.g. Shneker & Elliot, 2008). In such cases, it may be beneficial for clinicians to receive additional training in this area. Such training may help to increase clinicians' confidence in their ability to manage the condition, and greater awareness of interventions that might be beneficial for their clients. Moreover, training should involve a consideration of the attitudes that clinicians hold towards individuals with DS, and the impact that stigmatising views may have on the healthcare experiences of such individuals.

While it may be particularly important to increase awareness of best practice among clinicians who have infrequent contact with DS, more specialist clinicians such as psychiatrists and neurologists may also benefit from further training in order to enable greater consistency in the interventions and explanations received by presenting clients. It may be beneficial for specialist multidisciplinary professionals to strive for a 'common language' regarding the conceptualisation of DS (Jimenez et al., 2015). As suggested by Jimenez and colleagues (2015), this may be achieved by adopting the explanatory framework that incorporates biological and social factors, alongside predisposing, precipitating and perpetuating psychological factors.

Finally, while providing additional training to clinicians may help to increase the knowledge and confidence levels of clinicians involved in the care of DS, it may

also be valuable for clinicians to reflect on the limitations of our current understanding of DS, and to manage any anxieties and insecurities that may arise as a result of this limited understanding. Personal admissions of ignorance, such as those displayed by some of the therapists interviewed by Quinn and colleagues (2010) may be valuable, as they allow the clinician to approach clients with an open mind and a suitable degree of humility. Indeed, clinician humility has been advocated as a useful quality by Brown and Reuber (2016): 'It may be more therapeutic to present patients with a range of different ways of thinking about their difficulties... than to assume that we always "know best"'. The family therapy concept of 'safe uncertainty' may be a valuable one for clinicians working with a complex, multifactorial difficulty such as DS (Mason, 1993). Rather than feel it is necessary to quickly assume a position of certainty regarding the nature and treatment of a client's difficulties, it may be more profitable to accept an initial position of uncertainty and gradually evolve an understanding of the problem through collaborative exploration (Mason, 1993).

Implications for future research

Despite the perceived centrality of psychological interventions in the treatment of DS (Mayor et al., 2011), limited evidence was identified regarding the opinions and experiences of clinicians providing psychological therapy to individuals with this condition. There was a suggestion in two studies that such clinicians may differ from medical colleagues in their conceptualisation of the condition (Jimenez et al., 2015; 2016), with psychologists and psychotherapists preferring a biopsychosocial formulation approach over a multiaxial diagnostic approach. Such differences suggest that further exploration of the opinions and experiences of psychological therapists

regarding DS might provide useful, novel insights into the understanding and treatment of this condition.

Moreover, while one paper did explore the understandings and experiences of therapists treating DS in more detail (Quinn et al., 2010), it appeared that participants' theoretical orientation was primarily psychodynamic (though this was not made explicit). It is likely that clinicians working within a psychodynamic model would be inclined to adopt particular assumptions regarding etiology and treatment, (such as assuming a prominent role for traumatic experiences and the need to resolve unconscious conflicts (Breuer & Freud, 1957)). Therefore, it is important for research to consider the experiences of therapists working within other therapeutic modalities. In particular, given that Cognitive Behavioural Therapy is currently the therapeutic modality with the best evidence-base for the treatment of DS (Martlew et al., 2014), it would be valuable to explore the experiences of therapists providing this type of therapy.

Despite the amenability of the area of investigation (clinician experiences and opinions) to qualitative investigation, it was notable that very few studies identified employed a qualitative methodology. Qualitative methodologies employing semi-structured interviews have been usefully employed to understand the experiences of clinicians regarding the broader categories of 'conversion disorders' and 'medically unexplained symptoms' (e.g. Kanaan, Armstrong, Barnes & Wessely, 2009; Kendall et al., 2012). Quantitative survey-based methodologies may not provide participants with the scope to fully express their thoughts regarding this complex and nuanced condition and its treatment. Indeed, this issue was raised by Worsely and colleagues (2011), who felt that their survey did not always capture the true views of respondents, suggesting that 'it would be prudent for future studies of the illness

perceptions of health care staff to include not only self-report questionnaires... but also qualitative analysis of more in-depth interviews' (p. 672). Such studies should include all of the key professions involved in the care of individuals with DS, including primary care staff, neurologists, psychiatrists and psychological therapists.

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Part B

Section B: Exploring the experiences of therapists providing structured Cognitive Behavioural Therapy for dissociative seizures within the context of a randomised controlled trial

Word Count: 8,000 (plus 238 additional words)

For submission to 'Seizure'

Abstract

Purpose: A multicentre RCT is currently being undertaken to evaluate the effectiveness of structured Cognitive Behavioural Therapy (CBT) in treating Dissociative Seizures (DS). While this trial will provide data regarding the effectiveness of this intervention, further insights may be provided by considering the subjective experiences of participating clients and clinicians. In view of this, and limited research concerning clinician experiences of treating DS, this study explored therapist experiences of delivering this intervention.

Methods: Thematic Framework Analysis was used to analyse semi-structured interviews conducted with twelve therapists.

Results: Six overarching themes were identified: 'Varying applicability of intervention components', 'Multiple and complex difficulties faced by clients', 'Working effectively within the protocol', 'Limitations of protocol', 'Significance of formulation' and 'Quality of standardised medical care and difficulties of diagnosis delivery'

Conclusions: Interviewees encountered clients who they perceived to be experiencing multiple, complex difficulties. Some aspects of the intervention were considered more consistently applicable, and therapists stressed the need for a formulation-driven approach in which relevant intervention aspects were prioritised. Therapists felt that their clients' level of diagnostic understanding was variable at presentation, but reported that their clients benefitted from the standardisation of neurological and psychiatric medical care.

Keywords: *Dissociative seizures, Psychogenic nonepileptic seizures, Cognitive Behaviour Therapy, Treatment*

Introduction

Dissociative seizures (DS) have been described as attacks or 'episodic disturbances' (Brown & Reuber, 2016) that resemble epileptic seizures, but do not have any identifiable organic cause, and cannot be better explained by another psychiatric diagnosis (American Psychiatric Association (APA), 2013). The appearance of DS have been described as being 'superficially' (Rawlings & Reuber, 2016) similar to epileptic seizures, but research has identified several features that assist differentiation. These include (in the case of DS): longer duration, wakefulness, fluctuations in seizure course, pelvic thrusting, asynchronous movements and memory recall (Avbersek, Sisodiya, 2010). The 'gold standard' for diagnosis is considered to be the use of video electroencephalogram, in which the presence or absence of epileptiform brainwave activity can be established during a seizure (LaFrance, Reuber & Goldstein, 2013).

Research into the phenomenology and semiology of DS has led to the development of psychological models of the condition. One such model is the 'panic without panic' model, in which DS are conceptualised as a response to autonomic arousal similar to panic attacks, but without the presence of subjective anxiety (Goldstein & Mellers, 2006). Studies employing participant self-report and biometric measures have provided evidence to support this view. Individuals with DS have been observed to have a significant pre-ictal heart rate increase (Reinsberger, Perez, Murphy & Dworetzky, 2012), and report significantly more somatic symptoms of panic than individuals with epilepsy (Hendrickson, Popescu, Dixit, Ghearing & Bagic, 2014). Smaller studies have found a higher incidence of somatic symptoms of anxiety, without subjective anxiety (Galimberti, et al., 2003; Goldstein & Mellers, 2006). The evidence that individuals with DS exhibit avoidance behaviour has also

been cited as a shared characteristic of DS and panic attacks (Goldstein, Drew, Mellers, Mitchell-O'Malley & Oakley, 2000; Goldstein & Mellers, 2006; Dimaro et al., 2014).

An implication of this panic-without-panic model is that DS should be amenable to treatment with psychological therapy. If symptoms are sustained by particular cognitive and behavioural processes rather than by an organic deficit, it may be possible to disrupt these processes. Research has examined the efficacy of various psychological approaches, including psychotherapy (e.g. Barry, et al., 2008; Kuyk, Siffels, Bakvis & Swinkels, 2008), hypnosis (Moene, Spinhoven, Hoogduin & van Dyck, 2002; 2003) and paradoxical therapy (Ataoglu, Ozcetin, Icmeli & Ozbulut, 2003). However, a systematic review concluded there was 'very little high quality evidence' to support the use of any specific intervention for people with DS (Martlew, Pulman & Marson, 2014). A randomised controlled trial (RCT) examining the use of Cognitive Behavioural Therapy (CBT) in the treatment of DS (Goldstein et al., 2010a) was identified by the authors as providing the best available evidence of an effective intervention for people with this condition (Martlew et al., 2014).

Cognitive Behavioural Therapy (CBT) has been suggested as a logical choice of therapy for DS, given its focus on making cognitive and behavioural processes explicit (Brown, 2004). Two key strands of research have sought to demonstrate the applicability of CBT to the treatment of DS: the 'CBT-informed psychotherapy' (CBT-ip) approach (LaFrance et al., 2009) and an approach based on a fear-avoidance model (Chalder 1996). The CBT-ip approach involves a 12-week structured intervention that incorporates psychoeducation, identification of triggers, relaxation techniques and interpersonal communication (LaFrance, 2009). A four-arm RCT found that seizure frequency was significantly reduced in the CBT-ip group relative to

baseline, while no significant reduction was observed in a flexible-dose sertraline condition (LaFrance et al., 2014). However, the study had insufficient power to detect significant differences in seizure frequency between treatment groups, or 'group x time' interactions (LaFrance et al., 2014).

Research concerning the efficacy of a fear-avoidance approach to the treatment of DS has progressed through several stages of development (in line with Medical Research Council) concerning the development of complex interventions (Craig, Dieppe, Macintyre, Michie, Nazareth, & Petticrew, 2008)). In an initial case study, a pattern of fear-avoidance was observed in a client with DS (Chalder, 1996). Following intervention with CBT (including shared formulation, thought recording, thought challenging and exposure), a cessation in the client's seizures was observed. A pre-post study (N=16) employing a 12-session structured intervention based on this case study was then undertaken. Researchers observed a significant reduction in seizure frequency, and improvements in employment status, mood and anxiety that were maintained at 6-month follow-up (Goldstein et al., 2004). A small (N=66) single-blind RCT employing the same intervention was subsequently undertaken (Goldstein et al., 2010a). After 12 sessions of CBT alongside standard medical care, the treatment group exhibited a significant reduction in seizure frequency at the end of treatment relative to a standard medical care control group. However, this difference did not reach significance after six months ($p=0.08$). The authors noted that the limited sample size may have meant that the study had insufficient power to detect a difference at follow-up.

Building on this research, Goldstein and colleagues (2015) have been undertaking an adequately powered effectiveness RCT. This trial has been named the 'CODES trial', i.e. COgnitive behavioural therapy vs standardized medical care for

adults with Dissociative non-Epileptic Seizures. In this trial, 368 individuals with DS have been randomised to receive CBT in addition to Standardised Medical Care (SMC), or SMC alone. SMC in the CODES study is described by Goldstein and colleagues (2015) and includes a particular approach to the delivery of the diagnosis and the provision of information leaflets by neurologists and psychiatrists. The CBT intervention consists of 12 sessions intended to be delivered over 4-5 months. The session structure was based on Chalder's (1996) case study, and developed through subsequent studies (Goldstein et al., 2004; 2010a; Goldstein, LaFrance, Chigwedere, Mellers & Chalder, 2010b). The sessions include five treatment stages: engagement and psychoeducation, techniques for seizure management, reducing fear avoidance and use of exposure, identification and challenging of seizure-related cognitions, and relapse prevention. In keeping with generic CBT approaches (e.g. Greenberger & Padesky, 1995), this approach encourages clients to conceptualise their seizures as events that arise from an interaction of environmental triggers, behaviour, thoughts, emotions and physiological processes (Goldstein et al., 2015). Therapists delivering the therapy are provided with a manual that presents a session-by-session guide for the intervention, and clients are provided with their own handbook containing supporting material for the intervention. Therapists receive telephone-based group supervision every four-to-six weeks.

While the RCT study by Goldstein et al. (2015) will provide quantitative evidence regarding the effectiveness of the intervention, further valuable information could be obtained regarding the subjective experiences of clients and clinicians involved. The importance of employing qualitative methodologies in order to identify the 'active ingredients' of an intervention, or to understand why some individuals respond to an intervention while others may not, is highlighted by the Medical

Research Council (2000). Therefore, the aim of the present study was to explore the experiences that CBT therapists had of providing the intervention through use of qualitative methods (semi-structured interviews). Together with the evidence from the RCT and other qualitative investigations (interviews with CODES participants and psychiatrists), this research aimed to better understand factors that might impact on psychotherapeutic interventions for DS.

A review of the available literature identified only one qualitative study that explored the experiences of clinicians providing psychotherapeutic interventions for DS (Quinn et al., 2010). The researchers employed grounded theory in an analysis of interviews with seven Australian psychotherapists. They concluded that clinicians formulated their clients' DS in terms of a means of communication: that clients had communication deficits, and therefore developed nonverbal means of expressing affect (Quinn et al., 2010). Therapists cited the need for a safe therapeutic space in order for clients to develop their communication abilities, and orientation to the present. This study differed from the present one in several respects: therapists saw only one client each, interventions spanned several years, and the treatment approach appeared to be primarily psychodynamic (Quinn et al., 2010).

The aim of the current study was to understand the therapists' experience of providing a new structured intervention, to clarify whether the therapists considered aspects of the intervention to be useful. Secondly, individuals with DS often experience other difficulties such as previous trauma, general anxiety, depression and early life adversity (Brown & Reuber, 2016). Therefore, one objective was to see whether therapists perceived that their clients experienced multiple difficulties, and to determine whether the therapists felt that it was possible to effectively apply a manualised, structured intervention in such cases. Thirdly, given the importance of

effective diagnosis delivery and multidisciplinary working in the care of people with FNDs (Stone & Carson, 2009), a further aim was to explore how therapists perceived the role of standardised medical care, and whether their clients had been well prepared for therapy.

Methods

Design

The study design emerged from a desire to understand the subjective experiences of therapists delivering a novel structured CBT intervention for DS. In addition, it was notable that very little research exists concerning the experiences of therapists providing any kind of psychotherapeutic intervention for DS. As such, it was felt that semi-structured interviews with clinicians delivering CBT for DS in the context of an RCT would yield useful data on this subject. Clinicians involved in an ongoing RCT were therefore invited to participate in individual interviews with MW. These interviews were then analysed using Thematic Framework Analysis (Furber, 2010), in order to identify recurring themes.

Qualitative methodology. Transcripts were analysed using Thematic Framework Analysis (TFA). This methodology was developed for use in research that develops and improves social and healthcare services (Furber, 2010). Its originators sought to develop an explicit and systematic process for analyzing qualitative data for the purpose of informing policy development (Ritchie & Spencer, 1994). The approach has been designed to sit within a pragmatic, mixed methods paradigm: it can be used alongside statistical analyses in developing solutions to human problems (Ritchie & Spencer, 1994; Gale, Heath, Cameron, Rashid & Redwood, 2013).

Thematic Framework Analysis is typically employed in the analysis of semi-structured interview transcripts (Gale et al., 2013). The approach has often been used in research examining the experiences of clinicians, and has been applied to diverse settings (Anthierens et al., 2014; Harding, Campbell, Parsons, Rahman, & Underwood, 2010; Smith et al., 2015).

Epistemological position The epistemological position adopted in defense of this paradigm is that of 'pragmatism' (Johnson et al., 2007; Howe, 1988). Philosophical pragmatism holds that ancient debates concerning the nature of reality and knowledge may never be resolved, and that we should focus on the consequences of adopting philosophical positions (James, 1907). In relation to social science, it seems unlikely that practical knowledge will be advanced by the exclusion of either qualitative or quantitative research (Howe, 1988; Johnstone et al., 2007).

Participants

Participants were recruited from a pool of 39 CBT therapists involved in the CODES RCT. These therapists were situated across 18 NHS trusts throughout the UK and included clinical psychologists, CBT therapists, counselling psychologists and nurse therapists. The therapists practiced in a variety of outpatient settings, including hospital-based services and specialist community-based settings.

Purposive sampling was employed: participants were selected in order to produce a sample that included diversity on certain characteristics. Where certain categories of individual are considered *a priori* to have a different perspective to offer, purposive sampling may be indicated (Robinson, 2014). Comparable studies have found that professional background and years' experience of working with DS appear to be associated with differing views regarding such conditions (Jimenez,

Bautista, Fan & Tesar, 2015; Worsely, Whitehead, Kandler & Reuber, 2011). Gender and practice region have also been considered relevant characteristics (e.g. Kanaan, Armstrong, Barnes & Wessely, 2009). Therefore, professional background and years' experience were prioritized as significant characteristics.

Sixteen participants were initially contacted via email to ask whether they would be willing to participate in these interviews. Attached to this email was information regarding the nature and purpose of the research. Consent was obtained via email response, and via a formal consent form completed immediately prior to the interview.

Of the 16, 13 potential participants were then approached again and 12 therapists from 10 different NHS Trusts agreed to participate. As can be seen in Table 1, the sample included a good level of diversity with regards to CBT experience, professional background, experience of working with DS and region of practice. The group had limited diversity in terms of therapists' age and gender.

Table 1
Participants' self-reported demographic information

Demographic characteristic	N	%
Age		
31-40	5	41.7%
41-50	7	58.3%
Gender		
Female	10	83.3%
Male	2	16.7%
Professional background		
CBT Therapist	1	8.3%
Clinical Psychologist	4	33.3%
Counselling Psychologist	2	16.7%
Neurological Physiotherapist	1	8.3%
Nursing	1	8.3%
Occupational Therapist	1	8.3%
Psychotherapist	2	16.7%
Highest level of CBT qualification		
MSc	2	16.7%
BSc	1	8.3%
Diploma	2	16.7%
No CBT-specific qualification	7	58.3%
Months of CBT training		
0-12 months	1	8.3%
13-24 months	4	33.3%
25-36 months	4	33.3%
37+	1	8.3%
Data not provided	2	16.7%
Years practicing as CBT therapist		
0-5	6	50.0%
6-10	2	16.7%
11-15	2	16.7%
16-20	2	16.7%
Prior experience of working with DS		
Yes	9	75.0%
No	3	25.0%
Prior experience of working with Medically Unexplained Symptoms		
Yes	10	83.3%
No	2	16.7%

Region

Greater London	4	33.3%
Midlands	1	8.3%
North East England	3	25.0%
South East England	2	16.7%
South East Scotland	2	16.7%

Procedure

Ethical approval. Approval to undertake interviews with clinicians involved in the CODES trial was sought and obtained from the London Camberwell St Giles Research Ethics Committee and the Health Research Authority (REC reference: 13/LO/1595). Additionally, a review panel at Canterbury Christ Church University approved the specific protocol employed in this research.

Study Procedure. Semi-structured interviews lasting 40-60 minutes were conducted with all participants. Such interviews have been employed in comparable research (Kanaan, Armstrong, Barnes & Wessely, 2009; Quinn et al., 2010). As other researchers in this field have suggested, an interview-based method of data collection allows for the collection of rich, detailed and nuanced data concerning the phenomena of DS and its treatment (Kanaan et al., 2009; Rawlings & Reuber, 2016).

A predetermined interview schedule was devised (see Appendix H). In order for the exploration of relevant concerns, the interviewer allowed for limited divergence from the schedule. The schedule was developed through several stages and reviewed by a qualitative research expert (JM) at King's College London and adjusted.

All interviews were conducted by MW, and where possible these took place face-to-face at the therapist's workplace. In three cases, geographical distance prohibited a face-to-face meeting, and a teleconferencing facility was used.

Telephone-based interviews have been employed in comparable studies (McMillan et

al., 2014). All interviews were recorded using an encrypted digital recorder, or the teleconferencing recording facility. The recordings were subsequently transcribed verbatim onto a Microsoft Word document with all identifying characteristics removed. The anonymised transcripts were analysed using NVivo 11 software.

Data analysis

As prescribed by TFA, the qualitative analysis employed here consisted of five stages. Initially, MW went through a process of *familiarization* with the data: reading and re-reading transcripts in order to develop initial thoughts regarding recurring ideas in the data (Gale, Heath, Cameron, Rashid & Redwood, 2013). Following this, a second stage termed 'coding' took place in which the researcher applies labels to these transcripts to indicate their interpretation of the content (see Appendices J and L). A second researcher (JR) also undertook these familiarisation and coding processes with a sample of the transcripts (see Appendix K), and annotations were contrasted in order to refine these initial ideas.

A third stage involved the present researcher (MW) developing a working analytical framework (see Appendix M): that is, ideas from the coding stage were grouped into common categories. While this initial theoretical framework emerged largely from the data, it was also informed by the *a priori* aims and theoretical background of the research (Ritchie & Spencer, 1994).

In a fourth stage, termed *indexing* (Furber, 2010), the working theoretical framework was applied back to the transcripts by the researcher (MW) to see how the raw data fits this framework. Adjustments to the framework were made as necessary. Once the indexing process was complete, the coded data was *charted*: excerpts of raw data were presented in a chart to illustrate a given category (Furber, 2010). In a final

stage - '*mapping and interpretation*' (Ritchie & Spencer, 1994) – the present researcher (MW) considered the connections and patterns between the charted categories, and any explanations that might account for these connections.

Results

As can be seen in Table 2, the process of mapping and interpretation yielded six overarching themes and 16 subthemes.

Table 2

Thematic framework

Thematic Framework	Subthemes
1. Aspects of the intervention favoured, while others not always considered applicable	a. Seizure control techniques considered useful b. Family involvement considered useful c. Usefulness of graded exposure dependent on presence and nature of avoidance
2. Multiple and complex difficulties faced by clients	a. Physical health difficulties b. Mental health difficulties

- c. Therapist skill required
 3. Working effectively within the protocol
 - a. Value of employing structured approach
 - b. Applicability to complex presentations
 - c. Possibility of flexibility
 4. Limitations of protocol
 - a. Sense of constraint
 - b. Limitations of intervention
 - c. Striking a balance
 5. Significance of formulation
 - a. Standalone value of formulation
 - b. Providing rationale for treatment and tailoring intervention
 6. Quality of standardised medical care and difficulties of diagnosis delivery
 - a. Quality of standardised medical care
 - b. Difficulties of diagnosis delivery

Theme 1: Aspects of the intervention favoured, while others not always considered applicable

Seizure control techniques considered useful. The majority of therapists reported that they found the seizure control techniques prescribed in the manual to be helpful in working with their clients. From the therapists' perspective, it seemed that their clients could initially feel that they had no control over their DS. Through the experience of deliberately exercising control over their attention through grounding techniques or distraction techniques, therapists felt that their clients could change their relationship with the seizures, and had a new sense of control:

'when people are able to disengage, use the grounding techniques and the refocusing... they can see that they can engage in... thinking other than about the seizures and switch that pattern of behaviour... that was a penny drop moment' (Interview 4)

Two therapists reported that the use of seizure control techniques could serve to delay seizures, but did not necessarily stop them from happening at a later stage. In one case, the therapist reported seizure delay was not considered to be useful by her client: the seizures were still considered inevitable and unavoidable. However, in another case, the therapist reported that the ability to delay seizures could benefit her clients: they gained sufficient control to reduce the extent to which the seizures disrupted their lives:

'It can give them a sense of control, and obviously it could make a difference if, if they know that they are not going to have it in an embarrassing situation, that if they know, say if they are going out to, I don't know a wedding'
(Interview 3)

Five of the interviewees reported that they considered the 'Distraction and Refocusing' techniques chapter of the patients' handbook to be of particular use. Two of the reasons given for this were that the chapter was written with clarity, and that clients responded well to the tangible, practical nature of the techniques described in this chapter. One therapist reported that the positioning of this chapter early in the handbook could encourage clients to adopt the techniques early on, and continue using them without much prompting:

'I think it's quite clear and they're also quite motivated to read the booklet at the start, whereas they taper off at the end and they don't necessarily need to read it any more because they have absorbed it. But the distraction-refocusing techniques because they can quite clearly in their minds apply that to themselves. So I don't tend to need to talk much about distraction-refocusing because they are already doing it.' (Interview 6)

Family involvement considered useful. Seven participants expressed their approval of the inclusion of a treatment component that focused on the role of family in treating DS. There was widespread agreement among therapists that families can play a very significant role in helping their relatives to recover from DS. Interviewees commented that clients' families had often had distressing experiences of their relatives' DS that may have led them to become somewhat overprotective, and that this approach was often not helpful in their clients' recovery:

'I think people kind of drop and they harm themselves, they may have knocked over a kettle and burnt themselves, so families have then become very protective and have maybe encouraged people to stop doing things from fear of them harming themselves.' (Interview 5)

Therapists welcomed the allocation of the third treatment session to meeting with family members, as this provided an opportunity to clarify the treatment rationale. The involvement of family from this early stage in treatment was seen as an effective means of introducing a more structured and 'hands-off' approach to supporting their relative with DS. One therapist also commented that this session provided the opportunity to gain further information regarding the seizures from an observer's perspective, while another reported that careful use of relative involvement aided client engagement:

'So at times one member of the patient's family would attend, and at times another would attend, and I think that improves engagement knowing whom to invite or offering the client control over who they would invite.' (Interview 4)

Three therapists observed that this new approach to managing DS within the family could be counterintuitive and difficult to adjust to. The encouragement to take a step back from protecting their relative could conflict with their existing beliefs concerning possible risks. Nevertheless, two therapists reported that observing families adapting well despite such pre-existing beliefs, and that they welcomed the opportunity to try a new approach:

'I think that the urge to fall back into the old habits was quite strong... But on the positive side, I think that they were actually quite ready and maybe, you know, happy to, you know use the information to take a little bit of a step back' (Interview 11)

Five therapists cited the chapter for family members in the patient handbook as a helpful tool in supporting family members to understand the recommended approach to DS. In two cases, therapists expressed surprise that this chapter had been read by multiple family members, and that this had supported consistency in their approach:

'I have given one to a family member, and even though they didn't speak English they seemed to kind of get it. And the family member was very supportive. Apparently then other family members read the booklet. And they were able to kind of follow the plan, and kind of learn about it' (Interview 11)

However, it should be noted that one interviewee suggested that it was important to not over-emphasize the role of family, and that there might be other systems around the individual that might in some way be perpetuating the dissociative seizures:

'there could have been a lot more scope to look at other things that might be perpetuating in the wider system... if you've got people in the family group acting in a certain way it can influence seizure behaviour. That's one thread, but there seemed to be quite a big onus on that' (Interview 10)

Usefulness of graded exposure dependent on presence and nature of avoidance. Consistent with the fear-avoidance model of dissociative seizures, the identification of avoidance behaviours and their reduction through graded exposure was a central component of this intervention. In line with this model, a significant majority of therapists reported that they encountered avoidance of some form in their clients. In some cases, therapists felt that they regularly encountered overt avoidance behaviours in their clients, and that these behaviours could be effectively treated through graded exposure:

'I think once they started to do some behavioural stuff and, and, and if they ...went out and did something and found that their anxiety went down, that was a 'light bulb moment' for some people.' (Interview 7)

However, three therapists suggested that there were limitations to the applicability of graded exposure in some of the cases. Overt behavioural avoidances were not always identifiable: some clients appeared to be leading normal social and work lives, and did not report a fearing particular situations. In such cases, therapists reported that it could be difficult to devise graded exposure tasks. Six therapists emphasised the role of emotional avoidance, and suggested that emotional avoidance could sometimes be present without obvious behavioural avoidances. In such cases, 'exposure' might be better conceived as exposure to avoided emotions:

'People were getting on with their lives as they normally would. I would say that the avoidance was really sort of an emotional avoidance. In which case being in the therapy was sort of facing that. You can't really do a graded exposure...' (Interview 2)

One therapist suggested that in some cases it did not seem accurate to conceptualise emotions as being 'avoided', since such clients appeared to be so disconnected from their emotional processes. In this way, clients were not so much avoiding their emotions, as entirely unaware of them. This therapist reported that such cases could be particularly challenging to work with within the context of this intervention:

'I mean maybe some of them might be avoidant, some of them might just not be aware of their... emotional state and their psychological wellbeing... I felt that working with these people I was working at a much more superficial level'
(Interview 5)

Theme 2. Multiple and complex difficulties faced by clients

All therapists reported that their clients experienced difficulties in addition to their dissociative seizures. Both comorbid physical and mental health difficulties were cited as a significant complicating factor by these therapists.

Physical health difficulties. Six therapists reported that some of the clients they treated in the course of the trial experienced significant physical health difficulties. Fibromyalgia, chronic pain, infections and cardiac issues were some of the issues that therapists reported were experienced by their clients. While therapists reported incorporating the experience of such conditions into their clients' formulations, the presence of these health difficulties could have an impact on the progress of treatment. The presence of such difficulties could serve to increase the anxiety experienced by clients regarding the undertaking of exposure exercises. Therapists reported attempting to incorporate these difficulties into their clients' formulations. However, in some cases the impact of such physical health difficulties and the associated anxiety could serve to make the intervention unfeasible:

'...someone who already has avoidance and anxiety, and then they have physical health issues on top of that and don't feel physically well enough to come to sessions' (Interview 5).

In addition to anxiety concerning diagnosed physical health problems, two therapists reported encountering clients who were very troubled by undiagnosed physical health problems:

'one client had so many on-going tests during our sessions, they had health anxiety as well as the seizures' (Interview 8).

Mental health difficulties. In terms of comorbidity with other mental health difficulties, all participants reported observing a diverse range of issues including

depression, obsessive-compulsive disorder and emotional instability. All therapists reported that traumatic life events had featured in their clients' presentations, though three therapists noted that trauma did not feature in all cases. In two cases, the therapist found that the intervention became dominated by risk factors associated with the disclosure of a trauma.

Several therapists also perceived social anxiety and low self-esteem to be a prominent feature of clients' presentations, and this could be a perpetuating factor in avoiding aspects of day-to-day life:

'Quite a few of the patients that I saw had an underlying social defectiveness or belief. And that that was sort of driving difficulties being in the world really. That fundamentally they were giving up. That was quite common actually...'
(Interview 2).

Therapist skill required. In view of the complexity that therapists observed in the difficulties experienced by their clients, three therapists suggested that it might be important that an intervention such as this should be delivered by suitably experienced and qualified clinicians. The presence of trauma histories and complex physical health presentations were cited as examples of client characteristics that required significant clinical skill to manage effectively:

'I think you have to understand the population. And I think you do need to have experience of complexity because you are not doing a cookie-cutter intervention at all.' (Interview 2).

Theme 3. Working effectively within the protocol

Value of employing structured approach. Ten therapists reported that they had had some positive experiences of working within the prescribed protocol. While

the sessional structure was not considered to be appropriate in every case, the ordering and pacing of the intervention was generally considered to be sensible and applicable to many clients. Four therapists reported that they found that the protocol could sometimes act as a useful touchstone in cases when it felt that sessions were drifting from the agreed focus of the intervention:

'I think errm I think people are always inclined to take things into areas that they find are interesting to them, but I think what is quite useful about having a structure like this is that if you want to bring it back you can do it quite easily.' (Interview 10)

Applicability to complex presentations. Seven therapists expressed a view that it was possible to apply this structured intervention effectively in cases where clients were experiencing multiple, complex difficulties. One therapist suggested that the structure could be particularly useful in cases where individuals had received an initial diagnosis of emotionally unstable personality disorder, as it could be containing for them to have a framework to work within. In general, therapists suggested that the presence of a prescribed structure could help to clarify the scope of the intervention:

'...they understood what the remit of the treatment was and how many sessions it was going to be... we had discussed what the treatment covered, but also what it hasn't been able to cover' (Interview 3)

Possibility of flexibility. Eight therapists reported feeling that they were permitted to have some flexibility in their relationship with the protocol. The need for flexible re-ordering and selective emphasis on certain aspects of the intervention was considered important in view of the diversity and complexity of clients encountered in the trial. Therefore, some therapists expressed relief that the supervision they received in the course of the trial permitted some flexibility in their relationship with the

manual. Three therapists reported that they felt a greater sense of freedom and flexibility as they became more confident in delivering the intervention and felt able to trust their own judgement:

'Yeh you just get more you know what you're – it's like any therapy you know what you're delivering you know you've got some wins under your belt...I think you've just got the confidence that you know, to kind of have a bit more flexibility' (Interview 1)

Theme 4. Limitations of protocol

Sense of constraint. A feeling of being constrained by the protocol was reported by five of the interviewees. Other interviewees reported that they might have felt restricted by the manual had they not felt that they were permitted a degree of divergence from the protocol. In some cases, therapists felt that the prescribed structure required prevented them from approaching cases in the 'freer' manner in which they had worked prior to the trial:

'...Yeh it felt more restricted, definitely. And it felt different to the way I'm used to working as well. I guess I wouldn't be following a manual, I would probably be working more directly with the needs of the patient' (Interview 9).

This could sometimes mean that therapists felt that they could not incorporate ideas and strategies that they might otherwise have considered applicable to their clients' difficulties, or that they sometimes had to act against their instincts:

'...the beliefs underpinning the model, being slightly different from my own, meant that it felt like I had a whole area of strategies and expertise and experience that I couldn't apply... I don't think it was a problem inherent in the

model, I think it was the difference between how I normally work and how I was being asked to work' (Interview 10).

Limitations of intervention. In some cases, therapists reported that they did not feel they could address certain clients' needs within the constraints of the protocol. At times, therapists reported that they would have sought to widen the scope and timescale to accommodate clients' needs, while in other cases they felt that clients may have benefitted from a more limited intervention. In the particular case of trauma, seven therapists reported that they had experienced cases in which they felt that clients were experiencing trauma-related issues that could not be sufficiently addressed within the protocol. In such cases, therapists reported that there was a need for further referrals following the intervention:

'One group responds really well and don't necessarily need any further support, well they don't need any support after that. You know, they don't need it. Then there's another group who respond well but they need extra support referrals for, usually trauma processing' (Interview 6)

Striking a balance. Three therapists suggested that there was an important balance to be struck between rigidity and flexibility in the delivery of the intervention. While these therapists viewed a dogmatic adherence to the protocol as an obstacle to effective engagement and appropriate sensitivity to client needs, the importance of retaining a focus on the overall structure and direction of the protocol was noted:

'It was a balancing act. On the one hand we do want to stick to the model, we want to stick to the schedule of the treatment sessions... it's just using your discretion, using your experience I suppose. It's just not being too liberal with that. There are constraints' (Interview 4)

Theme 5. Significance of formulation

Standalone value of formulation. Five therapists expressed a view that the process of formulation alone could be extremely beneficial for people. In some cases, it was reported that much of this value was derived from the understanding that arose from a coherent linking of the client's past experiences to their current experience of DS. Furthermore, therapists also reported that it could be helpful to link the relationships between the multiple difficulties that a client may be experiencing in the present. The development of this shared understanding could provide moments of significant insight for clients:

'...I think they kind of conceptualise the seizures in isolation from anxiety stress, early warning signs. So I think if you can kind of conceptualise it I think those are they kind of 'light bulb' moments for people' (Interview 1)

Four therapists reported that their clients related strongly to a formulation of their DS in terms of an adaptive, 'switching off' reaction to unbearable emotion. In some cases, the introduction of this narrative was sufficient to generate significant insight:

'The idea that it was too much and they were dissociating and that that may have been the reason for them starting. Most people could definitely relate to that' (Interview 2)

Providing rationale for treatment and tailoring intervention. The majority of therapists suggested that formulation played a crucial role in grounding the prescribed interventions in the client's experiences. By constructing a detailed formulation of the client's difficulties and the factors that may be perpetuating them, therapists perceived that clients were better able to understand the rationale behind the interventions. One therapist suggested that there was a risk of the model and its

associated interventions appearing 'just academic' without this personalisation and contextualisation. Moreover, in some cases therapists felt that the formulation indicated that intervention components should be prioritised over others, and that the intervention should therefore be tailored:

'I mean, there might have been sections that we maybe didn't use so much because it didn't come up in the umm, intervention, you know I mean maybe the formulation didn't warrant using some of the interventions that were suggested'
(Interview 9)

Theme 6. Quality of standardised medical care and difficulties of diagnosis delivery

Quality of standardised medical care. Eleven interviewees provided positive feedback on aspects of the standardised medical care that was being delivered in the Trial . Several interviewees reported that their clients had described positive interactions with neurologists or psychiatrists, with clients reporting that they felt that they had taken a good amount of time to listen carefully to their concerns. Six therapists commented on the value of the close working relationships that they had had with their medical colleagues in the context of this trial. Therapists felt that their clients benefitted from cohesive working with neurologists and psychiatrists, and that this helped to mitigate any sense that clients may have had that they had been abandoned by these professionals following their allocation to psychological therapy:

'I found that because of the trial and because of the procedures in the trial, I was able to more easily work with the neurologist who had diagnosed the person with the condition, who was also reviewing them, and the psychiatrist

as well which felt a bit more like integrative and joined-up care' (Interview 12)

In six interviews, therapists expressed a view that the quality of medical care received by clients within the trial compared favourably to that received otherwise. In some cases, therapists reported that, outside of the trial, their clients could sometimes have negative experiences of the medical care received prior to therapy, and that this could make the process of engaging clients in therapy more challenging. Therapists described aspects of the SMC approach that had seemed to improve this process. The provision of leaflets by neurologists and the standardisation of the explanation given to clients (Goldstein et al., 2015) were cited as two possible factors:

'I think it's definitely helped that the neurologists have a... set sort of spiel to say to the patients, more of a standardized talk. And I know they have a leaflet that they give to the patients at that stage... it has definitely improved the level of knowledge' (Interview 3)

However, one therapist did not share the view that the CODES trial SMC was superior to non-SMC medical care, despite the fact that participants were typically receiving a higher level of input:

'...the advantage of people who came through the trial was that they had seen both a neurologist and a psychiatrist ... I don't think there was any more or less understanding despite that extra level' (Interview 10)

Difficulties of diagnosis delivery. Therapists reported that clients presented with varying degrees of understanding regarding both their diagnosis and their reason for their referral to therapy. Five therapists reported that they had seen clients who had attended with a very good level of understanding at presentation. In such cases, therapists reported that the diagnosis had been delivered with clarity by both the

neurologist and the psychiatrist, and that clients could relate a coherent account of the condition. However, a similar number of therapists commented that there could be significant limitations to their clients' understanding of their diagnosis and treatment. Typically, clinicians reported that clients presented with a moderate level of understanding of their condition, and that this would include some appreciation that psychological factors were relevant to their difficulties:

'They would have some understanding, they wouldn't necessarily be able to join all the dots... but they will generally have a sense that it is a psychological model that is being proposed for their condition' (Interview 4).

Where diagnostic understanding was poor, therapists did not necessarily feel that reasonable efforts had not been made by neurologists and psychiatrists to explain the condition. Interviewees commented on the complicated nature of a DS diagnosis, and the difficulty of relating this concept in an intelligible way in a short space of time:

'If I asked 'What did Dr [X] or what did Dr [Y] tell you about...' they would be like 'errrrmm' but I think it's such a difficult concept for people to understand, so I don't think it's that they didn't hear it. I think they heard it and they tried their best, to try and get that over, but it's such a hard concept' (Interview 5)

Discussion

In exploring the experience of CBT therapists delivering a novel CBT treatment protocol for dissociative seizures within the context of an RCT, important insights into three areas of enquiry were yielded. In relation to the utility of particular intervention components, therapists reported that some aspects of the treatment

protocol could to be effective in helping clients and their families to manage or gain more control over DS. Therapists reported that strategies such as grounding, refocusing and distraction techniques were often adopted by clients, and could permit seizure cessation, interruption or delay. From the therapists' perspective, the increased control that such clients gained over their seizures appeared to be empowering for clients. Individuals who experience DS typically report a sense of powerlessness and uncontrollability regarding their seizures; therefore the introduction of any sense of control may be important (Green, Payne, & Barnitt, 2004). The protocol's emphasis on family involvement and psychoeducation was also considered to be a useful aspect of the intervention by a significant number of interviewees. By inviting family members to sessions, and providing psychoeducation materials specifically written for relatives, it seems that family members were engaged in the intervention, and were willing to try new ways of supporting their relatives. Exploring such alternative approaches may be valuable, as some individuals with DS report experiencing parental overprotection and difficulties with communication (Krawetz et al., 2001; Salmon, Al-Marzooqi, Baker, & Reilly, 2003).

The analysis of these interviews provided insights into therapists' views regarding the applicability of the intervention to a client group that can present with multiple difficulties. While therapists considered aspects of the protocol to be applicable to most of the individuals that they saw, the thematic framework suggested that therapists saw a need for any intervention to be tailored to the needs of the individual client. For many therapists, it seems that formulation was viewed as the bedrock of this tailoring process: that gaining a thorough understanding of the details of each individual's situation and difficulties was needed before an effective intervention could take place. In many cases, it seems that therapists perceived their

clients to be experiencing a multiplicity of difficulties, and that a coherent linking of these difficulties could be helpful in-and-of itself. This valuing of formulation (and a formulation-based approach to intervention) is consistent with research into the opinions of other clinicians in the care of individuals with DS, including psychotherapists, psychologists and epilepsy clinicians (Jimenez et al., 2015; 2016).

Similarly, therapists typically welcomed the presence of some kind of structure, but also indicated that flexibility was needed in order to engage clients in a productive intervention. Therapists suggested that it would be helpful for them to be able to exercise a degree of discretion in terms of which aspects of the protocol might be most applicable to the client that they had in front of them. The client's formulation may indicate that certain aspects of the therapy protocol are more applicable to the client's needs, while others may be less so. For example, in the case of graded exposure, therapists suggested that this intervention may only be applicable where the formulation indicates that overt behavioural avoidances are present.

In relation to therapists' perception of SMC in the treatment of their clients, the analysis suggested that therapists welcomed the structure and standardisation of medical care imposed by the trial protocol. By ensuring that clients received a predetermined explanation of their diagnosis from neurologists and psychiatrists, as well receiving psychoeducational materials, therapists reported that clients appeared to attend therapy with an increased level of diagnostic understanding relative to those clients seen outside the RCT. Nevertheless, the complexity of the diagnosis remained a challenge, and some clients appeared to remain unclear about their diagnosis and treatment.

Practice Implications

At present, the quantitative results of the wider RCT and other associated qualitative investigations have not been obtained, and it will be important to interpret these results in conjunction with the findings of these other aspects of the trial. Nevertheless, this study may provide some useful indications for clinical practice.

From the therapists' perspective, it seems that practicing clinicians should consider applying a structured CBT intervention of this kind in cases where individuals experience DS. However, therapists who work with clients with DS must be careful to formulate on an individual basis the difficulties of each person that they see, and should be aware that a straightforward 'one-size-fits-all' approach should not be adopted. An intervention may be most effective where the client's symptoms are clearly related to the specifics of their life experiences, and where particularly relevant aspects of the intervention are emphasised over others.

Another implication of this research is that clinicians should be aware that, under some circumstances, the use of a structured CBT intervention for DS may not be sufficient on its own to address a client's psychological needs. In some cases, it may be necessary for further referrals to be made, and additional psychological interventions for issues such as trauma may be required. While other psychological issues may be addressed to some degree within the context of the structured intervention, the interviewees suggested that the scope was sometimes too limited to address all difficulties.

Theoretical Implications

Triangulation of these findings with client interviews, interviews with other healthcare professionals and quantitative measures will be essential to clarify the

theoretical implications of this research. It may be tentatively observed that the analysis is consistent with a view of DS as a highly heterogeneous condition. Research suggests significant etiological, clinical and phenomenological variability among people with DS, leading to a conceptualisation of DS as a condition perpetuated by a complex interaction of multiple diverse factors (Brown & Reuber, 2017). In the present study, therapists reported clients differed in the extent to which aspects of the intervention applied to them: personalisation of the intervention was necessary to accommodate this variation. Implicitly, DS may be caused and sustained by a different combination of biopsychosocial factors in different individuals. Nevertheless, the apparent applicability of this structured intervention to diverse presentations suggests there may be a limited number of perpetuating factors (such as those associated with attentional focus and avoidance) common to many individuals with DS.

Limitations

While the number of participants involved in this study was comparable to similar studies and represented a significant proportion of all the therapists involved in the RCT, the sample size remained small. A larger number of participants may have permitted greater confidence in the generalisability of the findings.

This study employed a purposive sampling technique. Given the small target population and the constraints of the resources available for this study, it was felt that it was necessary to use this strategy in order to achieve a good level of diversity with regard to relevant characteristics. Nevertheless, it should be acknowledged that, unlike participant self-selection or randomised sampling, this sampling process is open to researcher bias, as some participants may be approached rather than others.

In relation to practice region, trust affiliation, professional background, experience of providing CBT interventions and experience of working with this client

group, it seems that purposive sampling yielded a good level of diversity. However, it was not possible to achieve a good level of diversity in relation to gender and age. Nevertheless, the skew towards female therapists is consistent with the demographics of therapists in the wider trial, and with those of psychotherapy professions (e.g. Clearing House for Postgraduate Courses in Clinical Psychology, 2014).

Future Research

This study has only provided insights regarding clinicians' perspective on delivering this intervention. Clearly, it is essential to understand the subjective experiences of those individuals who were receiving the intervention, and hence a parallel project is currently being undertaken to gain some insight into this. Moreover, the findings of such a study, the present study, a qualitative investigation of SMC clinicians' experiences in the RCT and the main RCT findings should be considered together in order to ensure that the subject under consideration (the provision of structured CBT for DS) is viewed from different angles and with different methodologies. This process of 'triangulation' should allow for a more confident understanding of the intervention, and reduce the possibility of findings arising as a result of a methodological artefact (Johnson, Onwuegbuzie & Turner, 2007).

The finding that therapists often perceived the family involvement component of the intervention to be particularly beneficial may suggest that family therapy could be a valuable intervention for this population. However, a systematic review of interventions for DS (Martlew et al., 2014) identified only one study that involved the use of family therapy (Kuyk, 2008). The study was reported to be at high risk of bias, and only included family therapy as one among several different interventions applied

to participants. Therefore, a robustly designed study examining the use of family therapy in the treatment of DS could be a valuable consideration for future research.

Reflexivity

The process of qualitative data analysis also takes place within the context of power relations (Karnieli-Miller, Strier, & Pessach, 2009). While the process of analysis included more than one researcher, and researchers attempted to be mindful of their own biases, the researchers' own biases, agendas and prejudices will have inevitably influenced the product of the analysis. The research took place within the context of a large RCT. The interviewer was not involved in the wider trial, and attempts were made to conduct the interviews in a manner that encouraged the open sharing of opinions. However, the interviewer may nonetheless have been considered a representative of the wider trial, and participants may have felt pressure to respond more positively than they may have done otherwise. In order to acknowledge the subjectivity and potential for bias inherent in this research process, a research diary (see Appendix I) was kept in order to detail the reflections of the researcher, and evidence of the stages of qualitative analysis are detailed.

Conclusions

Through analysing interviews with therapists delivering a structured CBT intervention for DS, important insights were yielded regarding their experience of delivering this intervention, their perception of the client group, and their experience of working in conjunction with neurologists and psychiatrists. The thematic framework suggested that interviewees encountered clients who they perceived to be experiencing multiple and complex mental and physical health difficulties in addition to DS. Nevertheless, while some therapists reported cases in which they felt that the

prescribed intervention was not always adequate, therapists reported that the structure and focus provided by the intervention could be very useful in working with complex cases.

Therapists reported positive experiences of applying components of the intervention such as seizure control techniques and family involvement, but also stressed the need for a formulation-driven approach in which relevant aspects of the protocol were prioritised. While therapists felt that their clients' level of diagnostic understanding at the commencement of therapy remained variable, a significant number of therapists reported that their clients appeared to benefit from the standardisation of neurological and psychiatric medical care.

While this qualitative analysis of therapist experiences provides useful insights in isolation, it will be important to employ these findings alongside other research in gaining a greater understanding of this intervention through multiple perspectives and methodologies. Such research will include a quantitative analysis of intervention efficacy, and interviews with clients.

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Section C

Investigating clinicians' understandings and opinions regarding dissociative seizures, and exploring their experiences of providing interventions for individuals with this condition.

Appendices of supporting material

Appendix A

Scoring guidance notes for Quality Assessment Tool for Studies with Diverse Designs (Sirriyeh, Lawton, Gardner & Armitage, 2011)

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. 'in primary care'.	General description of research problem in the target population, e.g. 'among GPs in primary care'.	Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test-retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process (Qualitative only)	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

Appendix B
Application of Quality Assessment Tool for Studies with Diverse Designs

	Methodology	Statement of aims/objectives in main body of report. Aims rooted in existing literature	Clear description of research setting	Representativeness: sampling method	Representativeness: demographic information	Representative sample of target group of a reasonable size	Description of procedure for data collection	Rationale for choice of data collection tool(s)	Detailed recruitment data	Fit between stated research question and method of data collection (Quantitative)	Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	Fit between research question and method of analysis	Assessment of reliability of analytical process (Qualitative only)	Evidence of user involvement in design	Strengths and limitations critically discussed
Aatti et al., 2016	Quant	3	3	1	3	3	3	3	3	3	N/A	3	N/A	0	3
Notes				Self-selected from broad internet survey	Gender, age, experience, practice location, theoretical orientation and DS training collected	Relatively high response rate (36%) represented 10% of all French psychiatrists		Use of tool with previously demonstrated reliability				Use of inferential statistics to compare sub-groups			
Asadi-Pooya, 2016	Quant	2	3	2	3	1	3	1	3	3	N/A	3	N/A	0	0
Notes		Broad aims reported, limited consideration of existing research		opportunity sampling, regional sample	gender, age, experience, and location collected	Very small sample, target group size not reported		No background for questionnaire or details of quality assessment provided				Appropriate use of descriptive statistics only given limited scope and small sample			

Harden et al., 2003	Quant	3	3	1	2	1	1	0	3	3	N/A	3	N/A	0	0
Notes				Opportunity sampling of individuals attending special-interest conferences.	only experience collected	Sampling focused on individuals attending special-interest conferences.	Inference can be made that paper questionnaire was given out during sessions and then returned, but process not explicitly stated.	No explanation for choice of data collection tool. No evidence of statistical or non-statistical evaluation of questionnaire						a	No consideration of various limitations (e.g. regional nature of sample, also no consideration of implications of completing survey in group setting (presuming this was the case))
Jimenez et al., 2016	Quant	3	3	1	2		3	2	3	3	N/A	2	N/A	0	3
Notes				Self-selected from broad internet survey	Detailed information regarding clinical experience and theoretical orientation, but no age, gender or ethnicity			Detailed rationale and reference to prior use, but no mention of reliability and validity				Suitable method of analysis for quantitative data, no description of analytic process for open responses			
Jimenez et al., 2015	Quant	3	3	2	0	1	2	2	3	3	N/A	2	N/A	0	3

Notes				Opportunity sample of individuals in one regional centre	No demographic information provided	Small sample size: focused on individuals practicing in one regional centre	Precise method of survey distribution unclear	Relevance made clear, though no prior use or assessment of tool quality				Suitable method of analysis for quantitative data, no description of analytic process for open responses			
LaFrance et al., 2008	Quant	3	3	1	1	2	3	2/3	3	3	N/A	2	N/A	0	3
Notes				Self-selected from broad internet survey	Only profession and location	Reasonable (18%) response rate		Clear rationale and quality assessment (expert review and piloting). No reliability assessment			Sub-group comparison with inferential statistics not indicated by research question		Suitable method of analysis for quantitative data, no description of analytic process for open responses		
Mayor et al., 2011	Quant	3	3	1	2	1	3	1	3	3	N/A	2	N/A	0	3
Notes				Self-selected from broad internet survey	Profession, location, DS experience reported. No consideration of age or gender	Low (5.8%) response rate from target population		Limited description of rationale with no evidence of quality assessment			Sub-group comparison with inferential statistics not indicated by research question		Suitable method of analysis for quantitative data, no description of analytic process for open responses		
McMillan et al., 2014	Qual	3	3	1	1	2	2	3	2	N/A	3	3	3	0	3

Notes				Self-selected from internet survey	Only profession provided	Represented 10% of target population reasonable for qualitative design)	More details regarding number and method of responses needed, not just number of interview conducted		More details regarding number and method of responses needed, not just number of interview conducted						
O'Sullivan et al., 2005	Quant	3	3	2	1	1	3	1	3	3	N/A	2	N/A	0	3
Notes				purposive sampling	Gender included, but no indication of age, regional location, experience with DS or years experience	Small sample size: focused on individuals referring to one regional centre. Target group size not reported.		Limited description of rationale with no evidence of quality assessment				Suitable method of analysis for quantitative data, no description of analytic process for open responses			
Plioplys et al., 2014	Quant	3	3	1	3	1	3	1	3	3	N/A	3	N/A	0	2
Notes				Self-selected from broad internet survey	Gender, occupation, general experience and practice setting reported	Seemingly low response rate. Overlap in society membership obscured exact number. Skew towards academic respondents		Limited description of rationale with no evidence of quality assessment		Appropriate use of inferential statistics for sub-group comparison					No mention of response rate
Quinn et al. (2010)	Qual	2	3	1	3	1	2	2	1	N/A	3	3	N/A	0	3
Notes		Good		self-	Profession,	Very small	Location of	More detail	No indication						

		grounding in existing literature, aim could be more explicitly stated		selection via newsletter advertisement and snowball sampling	experience, setting, and gender plus demographics of clients	sample from very broadly defined target population. Sample included researchers	interviews not given, no interview schedule	on rationale for interviews and interview question desirable	of likely numbers approached						
Sahaya et al. (2012)	Quant	3	3	1	0		1	0	2	3	N/A	2	N/A	0	2
Notes				self-selected	None collected		Implied that this is a paper questionnaire, but not stated explicitly. Process by which distributed and responses gathered not clear	No mention of explanation for choice of this data collection tool. No evidence of statistical or non-statistical evaluation of questionnaire	No. approached/no. returned clear. No detail on manner in which people were approached			Inferential statistics needed given statements regarding comparison			Some limitations discussed, but not limitations of the analysis. More developed statement of nature of possible biases needed
Shneker & Elliot (2008)	Quant	3	3	1	3		3	2	2/3	3	N/A	3	N/A	0	3
				self-selected	Gender, location and years' experience collected			Authors outlined need for use of original unvalidated qnr	Only approximate figure for number approached given						
Whitehead & Reuber	Quant	3	3	1	3	1	2	3	2	3	N/A	3	N/A	0	3

(2012)															
				Self-selected from broad internet survey	gender, age, experience, profession	Seemingly low response rate. Overlap in society membership obscured exact number. Skew towards academic respondents	More details of additional opportunity sampling process desirable (e.g. number approached)	Previous application referenced, reliability and validity established, adaptation to study aims described	Number contacted in organisations approximate (and had overlap), number of colleagues approached not known. However all explicitly stated						
Whitehead et al., 2013	Quant	3	3	1	3	1	2	3	2	3	N/A	3	N/A	0	2/3
				Self-selected from broad internet survey	gender, age, experience, region	Response rate unclear due to non-reporting of proportion of society members who were neurologists	More details of additional opportunity sampling process desirable (e.g. number approached)	Previous application referenced, reliability and validity established, adaptation to study aims described	Clear data for patient participants, but no clear figure given for neurologists ('more than 1000' + unknown number through snowball sampling)						low response rate not explicitly mentioned
Worsley et al., 2011	Quant	3	3	2	3	2	2	3	2	3	N/A	3	N/A	0	3

				Opportunity sampling from single hospital setting	Age, gender and education included	Reasonable sample size, though target group size not explicitly reported	More details regarding details of questionnaire distribution desirable	Previous application referenced, reliability and validity established, adaptation to study aims described	Number approached not clear						
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Appendix C: Excerpt from overall trial protocol approved by Camberwell St Giles Ethics committee

“Qualitative analysis:

We will undertake a qualitative study to investigate the illness attributions, treatment preferences and experiences of trial participants. We will also seek interviews with ~10 staff involved in treatment in order to enhance triangulation, take into account institutional barriers or effects upon treatment, and to explore improvement in delivery as familiarity with the model and treatment developed over the life of the trial. Interviews with all participants will be digitally recorded and transcribed. Thematic Framework Analysis will be carried out by the RWs under the supervision of an experienced qualitative researcher; rigour will be increased by independent coding by at least two RWs followed by discussion meetings to agree a coding framework, to reduce bias in the interpretation of themes. Triangulation of the findings from the qualitative analysis with the results of the quantitative outcome measures will increase understanding of the trial process and may assist in understanding anomalies in outcomes.”

Appendix D:
HRA/NHS ethics approval for overall CODES RCT



Health Research Authority

NRES Committee London - Camberwell St Giles

Bristol Research Ethics Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1333
Facsimile: 0117 342 0445

18 December 2013

Professor Laura H. Goldstein
Professor of Clinical Neuropsychology
King's College London, Institute of Psychiatry
Department of Psychology, PO77, Henry Wellcome Building
Institute of Psychiatry, De Crespigny Park
London
SE5 8AF

Dear Professor Goldstein

Study title: COgnitive behavioural therapy vs standardised medical care for adultswith Dissociative non-Epileptic Seizures: A multi-centre randomisedcontrolled trial (CODES).
REC reference: 13/LO/1595
IRAS project ID: 136836

Thank you for your letter of 04 December 2013, responding to the Committee's request for further information on the above research and submitting revised documentation. The committee would like to thank you for your extremely detailed and thoughtful response.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mr Thomas Fairman, nrescommittee.london-camberwellstgiles@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Following your application the committee have concluded that this application should be SSI exempt, for the research procedures and processes as described in the application and supporting documentation.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		30 September 2013
Covering Letter		03 December 2013
Evidence of Insurance or Indemnity		26 September 2013
Investigator CV		26 September 2013
Other: Invitation sheet for caregiver to take part in seizure rating - Study looking at the effectiveness of different treatments in reducing dissociative seizures	1.0	26 September 2013
Other: Invitation sheet for Initial Diagnosis phase of study looking at the effectiveness of different treatments in reducing dissociative seizures	1.0	26 September 2013
Other: Invitation sheet for RCT phase of study looking at the effectiveness of different treatments in reducing dissociative seizures	1.0	26 September 2013
Other: Letter to GP for Initial diagnosis phase of study looking at the effectiveness of different treatments in reducing dissociative seizures	1.0	26 September 2013
Other: Letter to GP for RCT phase of study looking at the effectiveness of different treatments in reducing dissociative seizures	1.0	26 September 2013
Other: Letter from Funder		13 August 2013
Other: Measures for Study	2.0	01 December 2013
Participant Consent Form: Carers consent form for Comparing the effectiveness of different treatments for seizures, rating seizures	1.0	26 September 2013
Participant Consent Form: Participant Consent form, Initial Phase	2.0	01 December 2013
Participant Consent Form: Participant Consent Form, Randomised Controlled Trial	2.0	01 December 2013
Participant Information Sheet: Carer Information	2.0	01 December 2013
Participant Information Sheet: PIS, Initial Phase	2.0	01 December 2013
Participant Information Sheet: PIS, Randomised Controlled Trial	2.0	01 December 2013
Protocol	2.0	04 December 2013
Questionnaire: Measures for research into the effect of treatment on dissociative seizures		
REC application	1.0	26 September 2013
Response to Request for Further Information		04 December 2013
Summary/Synopsis	1.0	26 September 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical reviewReporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/1595

Please quote this number on all correspondence
--

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Mr John Richardson
Chair

Appendix E:

Ethical approval from Camberwell St Giles Ethics Committee for professionals' interview materials



Health Research Authority

London - Camberwell St Giles Research Ethics Committee

Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Tel: 02071048055

14 April 2016

Professor Laura H. Goldstein
Professor of Clinical Neuropsychology
King's College London
Department of Psychology, PO77
Henry Wellcome Building
Institute of Psychiatry
De Crespigny Park
London
SE5 8AF

Dear Professor Goldstein

Study title: COgnitive behavioural therapy vs standardised medical care for adultswith Dissociative non-Epileptic Seizures: A multi-centre randomisedcontrolled trial (CODES).
REC reference: 13/LO/1595
Amendment number: 6
Amendment date: 30 March 2016
IRAS project ID: 136836

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover letter for 6th substantial amendment]		23 March 2016
GP/consultant information sheets or letters [Letter to GP for End of Study]	1.0	17 March 2016

Notice of Substantial Amendment (non-CTIMP)	8	30 March 2016
Other [Professionals Invitation Letter for qualitative interview]	1.0	17 March 2016
Other [Participant invitation to qualitative interview]	1.0	17 March 2016
Other [8 Month Follow Up Letter for Uncontactable Patients]	1.0	17 March 2016
Participant consent form [Consent Form for Professional qualitative interviews]	1	17 March 2016
Participant information sheet (PIS) [Participant Information Sheet for Professionals version]	1.0	17 March 2016
Participant information sheet (PIS) [Patient Information Sheet for Randomised Controlled Trial Version]	3.0	17 March 2016
Participant information sheet (PIS) [Carer information sheet]	2.0	17 March 2016
Research protocol or project proposal [CODES Therapy Trial Protocol]	4	17 March 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/LO/1595:	Please quote this number on all correspondence
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Yours sincerely



Mr John Richardson
Chair

Appendix F:
Participant information sheet

[LOCALISED HEADLINE]

**COMPARING THE EFFECTIVENESS OF DIFFERENT TREATMENTS IN
REDUCING DISSOCIATIVE SEIZURE OCCURRENCE
(LREC LO/13/1595)**

PARTICIPANT INFORMATION SHEET

Thank you for your involvement in the CODES study to date. You are now being invited to take part in the qualitative aspect of the study. Please read this information sheet to help inform your decision about whether or not you wish to take part. If there is anything that is not clear or you would like more information about please discuss with the Research Worker.

1. What is the purpose of the study?

We have undertaken a study to look at treatment for dissociative seizures and to complement this we are conducting qualitative interviews and/ or focus groups with a selection of the professionals involved in the trial.

Through these conversations we aim to gain an understanding of your involvement with the trial, your experiences of delivering any treatments in line with the trial protocol, and your experience in general of working with patients with a diagnosis of dissociative seizures.

2. Why have I been invited to take part?

We are contacting you because you have been involved in the CODES trial in a professional capacity.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you are interested in taking part then you will be given the opportunity to discuss the interviews and/or focus group further with a member of our research team who will be helping to run the study for us.

If you do decide to take part you will be given this information sheet to keep and we will ask you to sign a consent form. After signing the consent form you are still free to withdraw at any time and without giving a reason.

4. What will happen to me if I take part?

We would arrange to meet (either 1-1 or in a focus group with others from your professional group), at a time and place to suit you, to have an informal conversation about your experiences of the trial and working with people with dissociative seizures. There will be specific questions you will be asked, but generally the focus of the conversation will be on your views and experiences. The conversations will be audio recorded in order to ensure an accurate record is obtained. Following the interviews the recording will be transcribed and analysed along with your peers' interviews to identify any common themes or experiences. You will not be identified in any accounts we then produce of the topics raised by people and any quotations

that we do use will not identify you. The recordings of the interviews themselves will then be erased to preserve your confidentiality

5. How long will I be in the study?

If you agree to take part, it is anticipated that a focus group would last for about 60 minutes and 1-1 interviews would last between 30- 60 minutes.

6. What are the possible disadvantages and risks of taking part?

There are no anticipated risks to taking part in this study and you will not be obliged to discuss anything that you do not wish to. The main disadvantage of taking part is the time commitment required; however, the research worker will arrange meetings to suit you in order to reduce this inconvenience.

7. What are the possible benefits of taking part?

By sharing your views and experiences you will be helping us to evaluate and assess the outcomes of the CODES trial in light of your professional experiences. This will inform the trial team about treatment from the professionals' points of view.

8. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. The research workers who contact you will need to keep your contact details at their university research sites but only for the purposes of contacting you about arranging to see you. This information will be securely stored and destroyed after the study. Any other information about you will have your name removed so that you cannot be recognised from it. We will not identify you in our computers or publications by name, and will only refer to you by Therapist Identification Number (TIN), which will be used in place of your name on any future publications. All information will be stored on password protected computers and paperwork will be stored securely in locked university offices.

We will keep the recordings that we make on an encrypted recording device or secure computers until they have been transcribed. These accounts of the conversations will not identify you in any way.

9. What happens to the results of the research study?

We will publish and disseminate the results of the work in peer-reviewed journals and at conferences and meetings. In addition we will talk to service providers about the results of our research. We will not identify you in any report/publication. If you would like a copy of the published results, we can provide this at the end of the study.

10. Withdrawal from the study

Taking part in this study is entirely voluntary. You can stop taking part in the study at any time without giving a reason, now or in the future.

11. Who is organising and funding the research?

The study is being funded by the National Institute for Health Research. The study is being organised by researchers at the Institute of Psychiatry (King's College London), the South London and Maudsley NHS Foundation Trust, the University of Sheffield, the University of Edinburgh and Brighton and Sussex Medical School. Members of the research team include Professor L. Goldstein, Dr J. Mellers, Professor T. Chalder, Professor M. Richardson, Professor M Reuber, Dr A. Carson, Dr J. Stone and Dr N. Medford, as well as several other colleagues who work with them.

12. Who has reviewed the study?

This study has been granted ethics approval by the London - Camberwell and St Giles Research Ethics Committee. The study has also been reviewed by the National Institute for Health Research Health Technology Assessment programme.

13. Contact for further information?

If you wish to discuss the study in greater detail then please contact one of the following people:

Iain Perdue
CODES Trial Manager
Dept of Psychology, PO 77
The Henry Wellcome Building
Institute of Psychiatry, Psychology and Neuroscience
King's College London
De Crespigny Park
London SE5 8AF

Tel 020 7848 0665

Other contacts:

Professor Laura Goldstein, Professor of Clinical Neuropsychology and Hon Consultant Clinical Psychologist; Dept of Psychology, Institute of Psychiatry (tel: 020 7848 0218)

Dr John Mellers, Consultant Neuropsychiatrist, Maudsley Hospital, London
(tel: 020 3228 2330,)

Professor Markus Reuber, Department of Neurology, Royal Hallamshire Hospital, Sheffield (tel: 0114 2268763)

Dr Jon Stone, Consultant Neurologist, Western General Hospital, Edinburgh
(tel: 0131 537 1167)

Thank you for reading this information sheet. You will be given a copy to keep. If you have understood the contents of this sheet and wish to take part, please complete the consent sheet. If you have any questions please feel free to ask them now.



This project was funded by the National Institute for Health Research HTA (project number 12/26/01)

Appendix G:
Consent form

[LOCALISED HEADER]

**COMPARING THE EFFECTIVENESS OF DIFFERENT
TREATMENTS IN REDUCING DISSOCIATIVE SEIZURE
OCCURRENCE: RANDOMISED CONTROLLED TRIAL
(LREC 13/LO/1595)**

CONSENT FORM FOR PROFESSIONALS

Name of Researcher:

Please initial each box

- I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions.
- Further, I understand that I may seek more information about the different
aspects of the study as it progresses.
- I understand that my participation is voluntary and that I am free to withdraw
at any time, without giving any reason.
- I understand that this interview and/ or focus group will be audio-recorded
using electronic recording equipment, to give an accurate record of the
conversation. I give permission for this.
- I give permission to this recording being transcribed (i.e. typed out) but that
my identity will not be revealed in this typed transcript.
- I give permission to aspects of what I might say during this interview being
quoted in reports about the study as long as my identity is not revealed. I
understand this may be used in partial fulfilment of a degree requirement by a
qualified student working with the study.
- I give permission for the research team to hold my personal information at
University sites for the purposes of this research and understand that this
information will be stored securely and confidentially and will be destroyed after
the study.
- I would like to receive a summary of the results of the study
- I agree to take part in the above study.

Name of Participant

Signature

Date



I confirm that I have explained the study and have answered any questions honestly and fully

Researcher

Signature

Date

1 copy for participant, 1 copy for study file.

Appendix H:
Semi-structured interview schedule

I) What opinion do CBT therapists have regarding the efficacy, flexibility and design of this CBT intervention?

1) How did you find the therapy manual and associated materials?

Possible sub-questions if needed:

a) How was it using the therapy manual/ the structure of the intervention on a sessional basis?

b) What did you think about the ordering of the sessions/ Was any re-ordering necessary

c) Which aspects of the intervention did you feel were easier/ more difficult to deliver?

d) Did you tend to direct clients to particular readings in the booklet for clients?/Were any of the chapters in the clients' booklet more/less useful?

2) How was it working within the CBT protocol? What would you say about the flexibility of this approach? (or was that what you meant by the question I added in above?)

3) *If this CBT intervention were to be rolled out across other services, what changes, if any, would you make to it?*

4) *If you were not working under the constraints of the trial, would you have applied a different therapeutic model, and if so what? Did that cause any tension for you?*

II) What experience do CBT therapists believe their clients had of the intervention? What experience did CBT therapists have of delivering the intervention?

1) What would you say about your clients' ability to relate the CBT model to their difficulties? How satisfying/meaningful did clients tend to find this as an explanation for their problem?

2) Were there any 'lightbulb moments' in the course of treatment where clients appeared to have a sudden understanding of their treatment? (*Prompt if needed: If so, at what point in treatment did this occur?/could you describe the nature of this moment?*)

3) Did the way clients engaged with therapy seem to change over time? (*Prompt if needed: Could you say something about the nature of this change*)

4) Did your experience of providing this intervention change over the course of the trial? (*Prompt if needed: If so, in what ways did this change?*)

III) What psychological processes did CBT therapists think that they were targeting in the intervention? Did therapists perceive individual psychological, social or health-related differences between clients that made it easier or more difficult for them to benefit from the CBT intervention?

1) What psychological processes did you think that you were targeting (directly or indirectly) in the intervention?

Possible sub-questions:

a) Did fear-avoidance feature in your clients' presentations?

b) If trauma was a significant feature of your client's presentation, how did you approach it in the context of this intervention?

2) Were there characteristics of clients that made it easier or harder for them to work with the treatment? (*Prompt: what were these characteristics? How did they affect the course of treatment? If we think about a particular client...*)

3) Were there issues that you had to address in order to improve engagement? (*Prompt: could you any examples of this? Were there any issues regarding timing/location/travel/childcare/need for relative support?*)

4) Could sessions ever become side-tracked/derailed by other issues? e.g.: social issues, safeguarding or health-related concerns (*Prompt: could you give any examples of this? How easy was it to come back to the focus of treatment?*)

IV) How did CBT therapists experience the overall care pathway, and how well integrated, in their opinion, were the CBT and SMC aspects of treatment?

1) What did you think about the overall care pathway? (*Prompt: How did SMC sit alongside the CBT intervention/ What would you say about the integration of these two aspects of treatment?*)

2) Did clients discuss their experiences of SMC in CBT sessions, and if so what did they report? In what ways did this seem to influence their understanding of their condition?

3) Do you feel that your clients understood their diagnosis? What do you think this diagnosis meant for them?

Appendix I:
Abridged research diary

October 2016

I have had to accept that my existing research project is not going to be feasible, and I will need to find another project for my course. I am disappointed in this, but hope that I will be able to find a suitable project that is within my same area of interest. I have learnt a lot about non-epileptic seizures and I would like to be able to apply this knowledge in whatever project I choose to do instead. If necessary, I may need to find another area of study, but I hope that I can find something that is at least loosely related. I have been speaking to my existing supervisor about other potential ideas. I am considering doing a project that might focus on the experiences of therapists working with nonepileptic seizures, and have started to formulate some research ideas.

November 2016

I have since met with a two clinicians who specialise in working with nonepileptic seizures. They have advised me that they are involved in the 'CODES' trial – a nationwide trial in which therapists are providing CBT to individuals with this condition. One of them suggested that this might provide an opportunity to interview a number of clinicians who have been providing the same intervention, and that this might provide a reasonable pool of clinicians from which to take original data (particularly considering such a large trial has not occurred before). I am excited by this idea, but am concerned that such a project may already be being undertaken. I have emailed my existing supervisor and she has agreed to contact the lead researcher for the trial (Laura Goldstein).

December 2016

I have met with Laura, and was pleased to find that I may be able to conduct an interview-based qualitative study as part of her overall project. I also met with Kip, her trial manager. Through the course of our conversation, we developed some preliminary foci for a potential interview schedule, including whether particular aspects of the intervention were considered useful or not, how therapists used the therapy manual, and how the therapists found working alongside neurologists and psychiatrists involved in the trial. We were unsure as to whether this project should incorporate interviews with medical staff, or whether this should be a separate project. I am hopeful that this may be a useful piece of research with practical applications, particularly given the limited research regarding therapists working with dissociative seizures. Nevertheless, I am also mindful that it will be important to try and maintain as much objectivity as possible in conducting such a project. Both positive and negative experiences of therapists must be reported, and not just those experiences that may reflect well on the intervention under consideration.

February 2017

Following further discussions with Laura and Kip, we have developed a more detailed interview protocol, and I have familiarized myself with the proposed methodology of Qualitative Framework Analysis. This is a methodology that seems to be clearly structured and applicable to research such as this. It is reassuring for me to know that a second researcher will also be coding some of the interview transcripts, as I hope that this will reduce the impact of my own biases on this work.

I am pleased that my new proposal has been approved by Salomons, and this process helped to clarify the need for the project to focus solely on therapists involved in the trial, and to not also include medical care clinicians. I agreed with this, as I was worried that the inclusion of multiple professional groups wouldn't allow for a sufficiently focused analysis.

It was also helpful to have the project proposal reviewed by a qualitative research expert at Kings. She suggested that purposive sampling focusing on particular, relevant characteristics (she stressed the need to particularly consider professional background) would be important, as a volunteer sample may limit the diversity of such characteristics. Also, it was helpful to rephrase some of the questions such that they might elicit richer responses.

March 2017

Since receiving approval from Salomons to go ahead with the project, there have been some delays on starting the process of recruitment, as administrative issues concerning my status as an external researcher have had to be addressed. This has been frustrating, as I would have preferred to start the process as quickly as possible. In the meantime, we have clarified the purposive sampling strategy, and have identified those clinicians who would provide a good mixture of professional background, regional representation, experience with DS and gender.

Early May 2017

Following recruitment emails sent to the first six identified participants last month, I was pleased to find that all of these clinicians were responsive to my request and cooperative in finding an appropriate date. This month, I met with my first three participants. Prior to meeting the first participant, I had some considerable apprehensions. I was concerned that the schedule might go on too long for them, or that the questions would not elicit much useful material. Instead, I found that all three participants appeared to have a considerable number of thoughts that they wished to share on their experiences. I was conscious of trying to avoid any leading comments, or to nudge the participants verbally or non-verbally towards statements that might be convenient for the wider trial.

Late May 2017

I have interviewed four further participants. In one case, the interview was conducted over the phone. This did change the experience of the interview somewhat – I could not see how the other person was reacting, and this may have led me to make more comments than I might have done otherwise in order to indicate that I was listening. I spoke to these participants within one week, and I was struck by contrasts in their reports. While one participant adopted a more critical attitude and stressed the need for divergence from the manual, another indicated that they adhered closely and found this to work with most clients.

I have transcribed several earlier interviews and am going through the process of familiarisation. Some themes already appeared to be emerging – the complexity of the clients they see, the varied amenability of clients to the model, and some parts of the intervention seeming to work better than others. I have given three of these transcripts to another research worker for her to familiarize herself with them and annotate them. I hope that my own annotations have some coherence with hers.

June 2017

I have met with four participants this month, and this has involved a lot of travelling. It now feels that many of the comments made by these participants fit into categories that I recognise from previous interviews. In one interview I did find myself feeling a sense of defensiveness – the participant was quite critical of most aspects of the intervention. However, I tried to remind myself that it is my role to report the honest opinions of the participating clinicians, and there is a very real risk of bias if I do not encourage participants to be open in all of their opinions regarding the trial. I reflected on the possibility that I may be scared to report negative findings back to the wider trial team, as these may be inconvenient. I am continuing to transcribe and familiarize myself with these interviews.

July 2017

Early this month I met with the research team at IoP. I compared my initial thoughts on possible themes from my process of familiarisation with those of the research worker who had read the transcripts. It appeared that there were many commonalities in the ideas that we had considered to recur in the interviews. These included ideas such as the challenge of managing complexity within the structured protocol, the value of certain intervention components (notably family involvement). We agreed that it would now be appropriate to develop and apply an initial theoretical framework.

September 2017

Following the meeting in July with the research team, I looked over my familiarisation notes and developed a theoretical framework. I have already had to cut out quite a lot of the codes I had come up with – there was just too much to manage coherently and to fit into the structure. I applied this back over the eleven transcripts that I have so far using NVivo and it seems to work. (Due to non-responsiveness of some therapists approached, I have yet to find a twelfth participant, and this is causing some anxiety). So far, the framework seems to fit well with the existing data, though it has been a painful process to exclude some interesting ideas that cannot fit within scope of this project. I am also starting to get a clearer sense of how the themes may relate to each other. I have started putting them into charts to see how the categories are spread across the different interviews – Nvivo helpful for this process. However, I think there may yet need to be some further refinement of the framework to increase the clarity and focus of the analysis.

October 2017

I have developed final version of the framework this month and have presented it to the research team at IoP. The framework was agreed as suitable, though a view was expressed that it would have been beneficial to have elicited more information regarding the materials used by therapists in the study. I hope that the existing analysis will still be useful to the team, and am concerned by this shortcoming. Nevertheless, I think that there was always going to be a limit on what could be coherently presented within the confines of such a project.

Once I had completed the process of charting the themes, I have been working hard to present the themes in a coherent way in my write-up, and have been 'mapping' these themes to clarify the connections between them. I am concerned that I need to aim for a suitable balance of positivity and negativity in the presentation regarding the intervention. Looking back over the process of analysis, I have found it interesting

that it was the therapists' critical comments that stood out to me, even though numerically they were outweighed by the level of positive comments regarding the intervention. Possibly I have been looking out more for the critical aspects due to my concern that I might omit 'inconvenient' feedback!

November 2017

At the start of this month, I had the opportunity to add an additional interview to the data. This was important in order to ensure a balance of demographic characteristics, but it was inconvenient as it meant that I may have needed to revise the theoretical framework. Thankfully, the interview generally accorded well with the existing theoretical framework. I did find in conducting this interview that I was less energetic than I had been in the past, possibly due to having conducted so many previously. I had to make more effort to be engaged, and I hope that this did not influence the content of the interview considerably. As I had experienced in some of the other interviews, I was also mindful that I was sometimes 'shutting down' what might have been interesting trains of thought due to the need to address the central questions of the interview protocol. I wonder whether a more open-ended approach could yield some interesting insights from therapists in the future.

I have continued to refine the write-up of the investigation. In doing so, I have reflected more on the potential for alternative interpretations of the raw data. While some of the transcripts were coded by another researcher, I wonder how differently the same data could be construed by researchers with alternative perspectives. I hope that my work would appear a reasonable interpretation by most people, had they the opportunity to look back over the data. I also hope that this information will prove helpful in improving these kind of interventions for people with this condition, and wonder whether the clients' perspectives would marry up with the views of the clinicians I interviewed.

It has been interesting for me to meet diverse clinicians from different parts of the country who were all dedicating themselves to the treatment of a very specific and relatively rare disorder. It was reassuring to see some commonalities between them, and to know that efforts are being made around the country to do something to help a group of people who have been traditionally sidelined.

Appendix J:
Example of transcript coded by MW

<p>So the first one I've got here is 'so how did you find the therapy manual and the materials associated with the manual?</p>	
<p>Yeh erm useful, nice to have the structure, umm the therapy in terms of the outline of the sessions, but also within that the flexibility to do what I would normally do in CBT which is an individual formulation and guiding treatment by the patient rather than specifically strict manual... I know that some CBT trials can be really specific about exactly what you have to do with each session... in a lot more detail than that. Which I think I would have found quite constrictive. So I think that was quite important that erm you could you know do a normal formulation you could do individual maintenance cycles... you weren't kind of forced to stay in one box</p>	<p>Good level of flexibility</p> <p>Positive comments re: manual</p>
<p>SO you felt you had a bit of scope to practice as you would like</p>	
<p>Yeh, yeh, but also it helped to have the structure of the manual to get you back to base if you were going off. Kind of like.. 'hang like, are we going off-topic a bit here?'</p>	<p>Value of having structure</p>
<p>SO you're saying it was a bit of a touchstone?</p>	
<p>Yes a bit of a touch stone. And of course there are 12 session so you do need to be tight</p>	<p>Helped to bring back focus</p>
<p>And in terms of you've kind of spoken a bit there about flexibility... did you feel you had flexibility or...</p>	<p>Possibility of flexibility</p>
<p>Yes I think so....</p>	
<p>Or were there times you felt constrained?</p>	
<p>Yeh, yeh, I felt constrained basically when patients had trauma histories that were very much relevant to their dissociative seizures. If they hadn't have been seen as part of the trial I would have done a trauma -focused treatment so in that way for those particular patients I felt constrained. But I mean I was just having a look through erm the trial patients, erm... that I've seen, two I'm still seeing. Errm you know that's not relevant for most of them. There's sort of four where its, no three, three to four where it would have been quite nice to have done some more trauma-focused work because it kind of felt like although avoidance might have been part of the picture it wasn't really the main issue, but actually kind of talking about the trauma... which we did</p>	<p>Sense of constraint/needs more flexibility</p> <p>Presence of trauma</p> <p>Limited scope to work with trauma</p>

<p>do but it wasn't enough time to do the full trauma treatment</p> <p>So in those cases you might have felt inclined to kind of, really take a trauma focused approach a bit more if you had more time</p> <p>Yes definitely. So I did with the cases when I could. But to fit it in in twelve sessions, you're quite constrained. And also being aware that you don't want to opening up boxes that you can't then contain...</p> <p>Okay, with regard to the other cases, are you saying that those ones, they were fairly doable within this approach?</p> <p>Yes, definitely I mean patients with presentations that were mainly an anxiety presentation – very anxious about the dissociative seizures, avoidance associated with that anxiety. Also, they worked very well within this kind of treatment approach. I think also what was useful about the treatment was that erm, which I think would have happened with any CBT interventions is that you're really getting people to understand their emotional state with reference to their thoughts and behaviours and feelings in their body,. And that's a really key part of treatment that people's emotional understanding improved as the treatment progressed. That they were able to tolerate different emotional states, to understand them more, to make links with their childhood. Errm, that I think was really important even though we focused on the current, it was important for them to understand why perhaps this was difficult for them. You know if they'd got shouted at as a child for expressing emotions it's understandable that they might find it difficult as an adult making those connections</p> <p>So in that regard, longitudinal formulation...</p> <p>I think it's incredibly key. I actually don't think. I think, just focusing on the maintenance may result in some improvements but I'm not... this is just my view... I don't think it's... I think they will come back with something else. That really in my personal view... What's at the root is the difficulty tolerating unwanted emotions. Understanding that experience that then comes out as a dissociative seizure.</p> <p>Okay. Actually I might return to the processes in a bit more focus in just a minute. If I just come back to the materials again, specifically with regard to the structure, so the sessional structure and the ordering of the sessions. What's</p>	<p>Limited ability to work with trauma</p> <p>Positive experiences of treatment for some types of presentation</p> <p>Value of CBT formulation</p> <p>Value of longitudinal formulation</p> <p>Importance of linking with early life experiences</p> <p>Centrality of emotion tolerance</p>
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<p>your opinion of that?</p> <p>Err yes, so I think it's good. Involvement of family in session 3 is really good. Getting a kind of formulation in session 1, session 2. Getting on board the rationale of dissociation I think is helpful for the majority of people if not all. I think I only had one patient where they just really didn't fit, but...</p> <p>What were the, were there any reasons as to why in that particular case was...</p> <p>Well I'm torn between whether she was incredibly alexithymic to the point that that was the problem, or, it just wasn't a problem. Like... I actually never really worked out that ... it was sort of this blankness of not anxious about them, not that bothered... quite disabling level of seizures. I mean there was even a question mark about diagnosis by the end, so I wonder whether actually she was having seizures that weren't visible on EEG</p> <p>Quite an unusual presentation?</p> <p>Very unusual. She was unlike all my other cases. And you know, we did the protocol, she engaged, she did the homework, it just made no difference whatsoever. Whereas everyone else, even the really complicated cases, who I think could have benefitted from more trauma-focused work, it still made a difference for them</p> <p>So you were saying that session 5, did you say the family...</p> <p>Session 3</p> <p>Session three – the family. And that was valuable?</p> <p>Very valuable. Including family, friends and partners, just to get everybody on board with the same message. And also to check out things that perhaps the patient hasn't told you. Errm, because the family members all have different views</p> <p>Did you feel that was an apt point to do it in the session structure or...</p> <p>Yeh... I think any later probably wouldn't work so well. And the danger earlier is you haven't got the patient engaged yet. You want them to know that you are on their side. I think that's important. And you also want to set up from the beginning them taking responsibility for their dissociative seizures</p>	<p>Value of family involvement</p> <p>Importance of understanding reason for dissociation</p> <p>Unclear why intervention didn't work in some cases</p> <p>Possibility of successfully intervening where trauma or complexity present</p> <p>Value of family involvement</p> <p>Consistency from family involvement</p> <p>Good structure/ordering of intervention</p>
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<p>And with regard to the different aspects of the interventions, which ones did you think were easier or which ones did you think were more difficult to deliver. So I suppose which parts were difficult to deliver, as a clinician, and which parts were easier or harder</p> <p>Where it was relevant graded exposure was perfect. But there were a few cases where it really, it wasn't really that level of avoidance. People were getting on with their lives as they normally would. I would say that the avoidance was really sort of an emotional avoidance. In which case being in the therapy was sort of facing that errm. You can't really do a graded exposure [inaudible] Sometimes you were kind of... yeh, you were kind of... I guess what would often happen was that you would get some underlying problems, so quite a few of the patients that I saw had an underlying social defectiveness or belief. And that that was sort of driving difficulties being in the world really. That fundamentally they were giving up. That was quite common actually and so doing behavioural experiments, errm making links was quite important, and that's; not really graded exposure that's much more cognitive than behavioural.</p> <p>With regard to any other aspects... are there any aspects of the intervention that were quite regularly difficult for you to deliver?</p> <p>Errm, no I don't think so. I think maybe it helps that I'm relatively experienced. I was confident to put my own, you know, to present a thought record how I would like to present a thought record, you know I didn't use theirs very often I used my own I prefer it. Errm, hmm.. The seizure diary was very helpful. I use that with patients out of the trial that's really good.</p> <p>~10min ??</p> <p>And they were willing to use that?</p> <p>Yes - variable! Generally people were quite good at completing it. Some had to yeh, push a bit... the use of it. Yeh... and there's something about the population where... umm... I guess I'll be interested about the trial outcomes in</p>	<p>Graded exposure not always applicable</p> <p>Absence of avoidance behaviour</p> <p>Difficulty of doing graded exposure in some cases</p> <p>Complexity of clients</p> <p>Presence of social anxiety/defectiveness belief</p> <p>Past experience of clinician helpful</p> <p>Value of seizure diary</p> <p>Difficulty with completing homework</p>
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<p>terms of how much we can say it's due to the CBT specifically umm... sort of the mechanisms and change involved you know becuas etehre's the seizure diary and that's... CBT in essence, but other treatments use diaries</p> <p>Mmmhmm</p> <p>The, you know reducing avoidance that's very CBT, but again wasn't necessarily relevant to all. Umm... yeh.</p> <p>SO actually knowing the extent to which, what the active ingredients were would be interesting</p> <p>I would be really interested in that. I mean I'm an BABCP accredited CBT therapist and a clinical psychologist and experienced working with complex presentations. And I guess I'm more in the point in my career where I'm questioning how things work than perhaps someone who is more novice, so that might just be my skeptcal vew at te moment</p> <p>Okay, that;s interesting</p> <p>Kind of the core things , the innards of what works</p> <p>And that is erm another relevant question, is: Is your own professional background, how do you think that might have influence your</p> <p>I think it would be very difficul for somebody who has done one year of CBT training to deliever this treatment effectively</p> <p>Mmmhmm</p> <p>I think you have to understand the population. And I think you do need to have experience of complexity because you are not doing a cookie-cutter intervention at all. Errm someone can't pick up that manual and deliver it. Well they can try but I really doubt it would work very well. You know- particularly the engagement initially. That's really</p>	<p>Difficulty of knowing what benefits are from CBT per se</p> <p>Avoidance not present in all cases</p> <p>Unclear whether CBT is active ingredient where intervention is successful</p> <p>Need for experienced clinicians</p> <p>Complexity of cases means intervention needs to be tailored</p> <p>Need for experienced</p>
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<p>important. And the formulation, getting people on board. And tehn of course, you know, they often have co-morbid difficulties. You need to have some understanding of that. Errm, yeh. I think it would be very difficult to deliver..</p> <p>So those are some of the factors that errm, you feel your past experience has really helped you inmanaging these things</p> <p>Definitely, yeh yeh, I used to work in a CMHT... so people who don't fit into models necessarily! Having to be quite creative and flexible. But applying the principles of CBT. So a kind of transdiagnostic approach.</p> <p>And I mean, sort of relatedly, if the intervention was to be rolled out across other services, what changes, if there were any changes, would you make</p> <p>I would be very concerned that if it was kind of rolled out as a kind of IAPT style, 12 sessions bing bang bosh, I, you know, it just, you know - no! (laughing) I just can't see it working. I did have to use my own formulation skills to deliver it effectively I think. I know I;m biased but -</p> <p>And if the intervention was, regardless of the particular service setting that it was, if it was other clinical psychologists such as yourself doing it, would there still be any, any things that might stand out to you that you would like to change about the...</p> <p>I guess, to have the option of kind of integrating a more trauma-focused approach when it's relevant (because it isn't relevant for everyone). So errm imagery rescripting, I'm not talking about exposure-type traima work, usually it's complex childhood trauma. SO imagery rescripting, EMDR, something tat's evidence-based for complex trauma. I think that would integrate well. Because I think people can kind of fit into the sort of panic-without-panic model,which is the model guiding this treatment. SO it's effectively a panic disorder model. But they might also have alongside it other things going on. Errm...</p> <p>Would you see that as an option.. because it sounds like that wasn't the case with everyone?</p> <p>No, no, but I guess it was different sort of emphasis for different people. SO for some kind of behavioural experiments were really really key. Like you know looking at one here: social anxiety was really majiore for her. So even when we had got the seizures down, that's what was coming</p>	<p>clinicians</p> <p>Need for flexibility</p> <p>Need for suitably skilled clinicians</p> <p>Need for more of a focus on trauma or trauma-specific interventions</p> <p>Appropriateness of panic-without-panic</p> <p>Need for emphasis on different aspects of intervention</p> <p>Presence of social</p>
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<p>out and getting in the way. So doing behavioural experiments around that, and understating that and getting her to tolerate emotions and test out her assumptions in social situations. I would say that... I don't know what the data says, but that it would probably help to keep her, I mean she was dissociative seizure free at the end of treatment and I think that social anxiety work may have helped to keep her well. You can't sort of.. yeh it's that kind of balance of 'okay we're treating dissociative seizures' and with some of them by session 5 or 6 they have stopped. And then what you are left with is 'Okay what might be going on alongside this, underneath this, that might be driving it. So often: anxiety or sort of social defectiveness is in, in my experience of this caseload... errmm</p> <p>Okay so scope to touch on those things or to provide avenues to explore other areas</p> <p>I think if it was strictly right errmm... you're panicking about the feelings of having the dissociative seizure and that's the problem. You know we need to test out those assumptions and we need to do graded exposure to reduce your avoidance. If it was only that, I don't think you can apply that to everybody.</p> <p>Okay</p> <p>I think it's a good model for a lot of people. But I don't think it's totally applicable to everyone</p> <p>Okay, errmm... moving on to ermm... sort of a few clinical details. So what would you say about your, your clients' ability to relate the CBT model to their difficulties, and how satisfying or meaningful did they tend to find this as an explanation for their problem?</p> <p>Yeh I think the CBT model generally is very well understood by patients. Are you talking about the panic without panic model?</p> <p>I suppose the mode as it's presented in here, which it quite focused on that, but includes other aspects...</p> <p>Yeh, well I think the act of breaking down into thoughts, feelings, behaviours, physical sensations, that in any given situation this is going on for you is really helpful for these patients who may particularly be people who struggle to identify their emotions. So I would often give people a feelings wheel, a list of 'feelings words' to help them think</p>	<p>anxiety</p> <p>Need for emotion tolerance</p> <p>Need for flexibility in number of sessions and use of sessions</p> <p>Presence of social anxiety</p> <p>Straightforward panic-without panic cannot be applied to all</p> <p>Model well understood</p> <p>Value of CBT formulation</p> <p>Difficulty identifying emotions</p> <p>Need for emotional</p>
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<p>'what is this I'm feeling?'. Because that sort of emotional education.. I think the CBT model of intervention is very good at delivering that in a way that's not, in a way that is quite palatable, that makes sense to people</p> <p>And they were able to relate that to their difficulties and current situations?</p> <p>Definitely, you know that the way they think about something affects the way they feel, or, the way they act in a situation affects the way they feel, and the way they think you know definitely... that wasn't a problem for anybody</p> <p>Okay</p> <p>But specifically the panic without panic model... yeh... hmm... the model of dissociation was more.. the idea that it was too much and they were dissociating and that that may have been the reason for them starting. Most people could definitely relate to that. You know – stressful events, or just the sort of the emotional processing style. Errm.. the reasons for it continuing, you could kind of identify that for some people it was always stress triggering them off. For others they would be quite relaxed - identifying it as a habitual response to similar feelings in the body. Poeples could relate to that definitely</p> <p>But specifically in relation to the panic without panic aspect, how relatable was that for people?</p> <p>Hmmm... I'm not sure. I'm just trying to... they would be aware often of feeling anxious. Particularly as treatment progressed, or you know, worrying about the seizures. At first they would say 'I don't think anything' or 'I don't feel anything', the more they kept a diary or the more we spoke about it, the more they would notice those little warning signs.</p> <p>Okay</p> <p>Yeh... so...</p> <p>Was there variation between cases on that relatability?</p> <p>Hmm... I don't know I mean I think the panic-without-panic model is useful for clinicians. I'm not sure it's... I'm not sure patients necessarily understand it. But I don't know</p> <p>Sure</p>	<p>education</p> <p>Relatability of CBT model for all</p> <p>Panic-without-panic not always relatable</p> <p>Value of concept of dissociation – overload</p> <p>Greater awareness of anxiety as treatment progressed</p> <p>Clients may not understand panic-without-panic</p> <p>Value of dissociation</p>
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<p>Yeh, Its certainly not something I would have gone on about. I would talk about dissociation and about what would you have done in response – what are you thinking, what are you feeling, what kind of links can you make there. Misinterpretation of the physical sensations, ermmm, using grounding strategies as a rationale ermm...turning attention away. SO in tha way, definitely the rationale in terms of paying attention to symptoms you find troubling escalates them SO turning attantion way using grounding strategy or a distraction strategy yeh, that was very relatable. So for lots of people that was very useful. Not for all, but for most. Most people found using grounding strategies very useful</p> <p>So grounding strategies, okay, thank you</p> <p>Sorry that was really convoluted</p> <p>No, no that was great thank you. Errmmm... so the next one is 'were there any 'light bulb' moments in the course of treatment, so where clients appeared to have a sudden understanding, were there ever occasions where it seems that there was a particular thing that was touched on that was...</p> <p>Hmmm.. that's a good questions. Let me just think about anybody... it's difficult to think about the ones from last year because that was quite a long time ago. Errmmm... yeh one of them, the lady who we sort of identified quite strong social anxiety after we had kind of got the dissociative seizures under control, definitely kind of , it was a 'light bulb' moment – identifying the social anxiety because it wasn't sort of immediately apparent. You had to do a bit of digging about. And then it was apparent that it was just so pervasive in how she dressed and how she went when she was out. In terms of where she went and how she thought about herself. People thinking about her. You know – it really affected her mood and her choice of activities. So, it wasn't immediately apparent. SO it wasn't like she came saying 'oh I'm really anxious socially',</p> <p>Yeh, but when that was identified as maintaining factor or a trigger...</p> <p>Yes as a kind of vulnerability because... her baseline anxiety was so much higher in social situations, because she was constantly evaluating what other people were thinking about her. And kind of her understating of kind of her self-directed attention was maintaining the anxiety was really</p>	<p>concept</p> <p>Usefulness of grounding techniques</p> <p>Value of distraction techniques</p> <p>Lightbulb moment from formulation including social anxiety</p> <p>General high anxiety related to social anxiety</p>
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<p>important for her. She totally, she took on the behavioural experiments. Totally transformed by it I would say, quite remarkable</p> <p>And that's, that's great. That relates in quite a specific way to that person. In any of the other cases were there times where, was there a kind of common thing you picked up on, where a couple of people kind of got it in a way?</p> <p>I'm sure there was, I'm just struggling to, to think about it. There was one errmmm, quite complex presentation of somebody who had a history of substance misuse. Lots of substances. Errmm... and kind of formulating with him the kind of avoidance of affect through substance misuse and then through the development for the seizures and then linking it back to when he [had a very significant rejection in his life] errmm... that was quite an important link for him to make</p> <p>Mmmhmm</p> <p>Errmm... yeh. So maybe a kind of commonality between those two is that, it's not, it's quite individualised, you've identified quite specific things</p> <p>Very specific - I mean recently there was someone I was working with. And she stopped having dissociative seizures by session 3 or 4. The seizures she understood were not so threatening, kind of understanding why it might have developed and things. They've stopped happening. But you know recently, the later sessions have been kind of working on her kind of underlying anxiety and her kind of constant worrying. Errmm... and recently had a session where errm, she was talking about umm.. you know feeling not good enough in an interaction and I asked her, 'What's your earliest memory of that. And she remembered [an early experience of humiliation] and kind of that was really important. And then we did a session on imagery rescripting and it's really helped her to, to kind of remember that kind of experience of ummm, I don't know whether you know about imagery rescripting?</p> <p>I'm not sure</p> <p>SO you get the person to recall th memory as if they are in the memory as a child. And you get them to go back into the memory as the adult self and experience it as their adult self seeing that child in need and giving the child what they need. And then they experience that memory again as the child in</p>	<p>Value of behavioural experiments</p> <p>Complexity – presence of substance abuse</p> <p>Lightbulb from formulation including other difficulties</p> <p>Value of idiosyncratic formulation</p> <p>Presence of general anxiety</p> <p>Presence of shame/humiliation</p> <p>Incorporation of trauma techniques</p>
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<p>need receiving that help that they need, and that support.</p>	
<p>Okay</p>	
<p>And I think for her having that experience of... umm... of helping herself, you know because he had the skills she just wasn't using them for herself. I mean it's early days. But has helped in other current situations she remembers that and remembers what she needs. That kind of compassion and nurturing</p>	<p>Use of self-compassion</p>
<p>Okay</p>	
<p>Yeh so that's been quite important... but equally, again it's not specific to dissociative seizures. But I guess it's these people where you kind of, in essence you kind of help with the dissociative seizures. And then the underlying issue...</p>	<p>Indirectly helping DS by addressing other issues in therapy</p>
<p>So through that underlying formulation taking in various factors, you're kind of not just focusing on that, but you're picking upon other things that might be maintaining general anxiety or whatever it might be?</p>	
<p>Yeh, yeh</p>	
<p>Okay (27:09) umm... did the way clients engaged with therapy seem to change over time? So I suppose through the course of the sessions did you notice any sort of...</p>	
<p>Umm I would say so I've only had one person drop out, and they dropped out in session two I think because they disagreed with the diagnosis</p>	<p>Low drop-out rate Disputing diagnosis</p>
<p>mmhmm</p>	
<p>And they stopped coming to the neurologist here and went to another one who would give them the diagnosis of epilepsy which is what they wanted. Ummm... but the rest I would say really liked coming to sessions</p>	<p>Positive experiences of the intervention</p>
<p>mmhmmm</p>	
<p>Very good engagement. Ummm.... really appreciated having a space to talk. Ummm...</p>	<p>Good levels of engagement</p>
<p>And was, I suppose was that generally maintained over the course of those sessions... That enthusiasm?</p>	
<p>Yeh, yeh, I mean some... I mean the nature of the population</p>	<p>Engagement sustained throughout intervention</p>

<p>is, some of them can be a bit kind of, can fit a bit too much into their day. And also where we are we cover a huge area, umm so it's not just local people, some people have to travel quite far. SO kind of the scheduling of sessions, so ensuring that they are regular all the time was sometimes a bit tricky.</p> <p>Okay, and that was something that I was going to ask that I can ask now which is... so that was something that had to be overcome a bit was those logistical difficulties, were there any other things that kind of could interfere, any practical things like that which could interfere in the course of therapy?</p> <p>Ummm... who needed patients transport, I'm sure some did... Oh one person came with a support worker. She had an ASD, autistic spectrum disorder diagnosis</p> <p>Mmmhmm</p> <p>She came with a support worker to every session. Err.... So, but that wasn't a hindrance to be honest that was quite helpful. The carer was a kind of co-therapist. Umm...</p> <p>And any other issues around kind of, might be location, err sorry timing or childcare or... relatives issues</p> <p>Ummm, childcare wasn't a problem for anybody. Ummm obviously sometimes people would have dissociative seizures in the session. But that was never a problem. Ummm, it was quite useful actually. Umm... yeh I mean intertingly I don't think, I mean I could just be misremembering, but I don't think anybody missed a session because of having a dissociative seizure</p> <p>Mmmhmm</p> <p>Which is quite interesting, probably a bit unusual actually. Because I'm sure some of my non-CODES patients have had them...</p> <p>Okay and when they did happen in the session... how was that, for you?</p> <p>Errmm, I mean I guess because I have kind of got used to it, it's never nice, ummm... but it's quite useful because then you can talk about it afterwards and you've go kind of a nice example right in front of you. SO you can kind of formulate it afterwards if they are able to sit with you and talk a bit about it</p>	<p>Logistical difficulties – travel distance barrier to engagement</p> <p>Client complexity</p> <p>Need for patient transport</p> <p>Use of carer as co-therapist</p> <p>DS could occur in session but could be used productively</p> <p>CODES clients had more consistent attendance than those outside trial</p> <p>Value of seizures occurring in session</p>
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<p>And do you feel that was effective?</p> <p>Yeh I think that's really helpful. I think for some patients it's quite important that you see them having one so that you understand how horrible it is</p> <p>So you are able to actually make quite effective use of it when it happens</p> <p>Yeh I certainly don't think it's a negative</p> <p>Okay...</p> <p>I'm sure if it was happening for the same of the session I'm sure it would be a bit more [inaudible, laughing]</p> <p>And you've personally been involved in the trial for a couple of years now then have you?</p> <p>Yeh since it started</p> <p>Since it started okay, and do you think your experience of proving the intervention has changes over the course of the trial?</p> <p>For patients within the trial?</p> <p>Yeh I suppose for patients in the trial</p> <p>Ummm... I don't think so. Mmmm... no I mean in terms of the structure was quite nice, you know, diary, planning strategies, family. Particularly the initial structure. Kind of really kind of forming the basis for the therapy, that was really useful. Ummm...</p> <p>What did you think about later then, so the first bit you feel was quite good in the regard, but the middle and later sessions...</p> <p>Well the middle bit is the tricky bit because it really depends n the individual in front of you... yeh... it depends what they are coming with really. Ummm... I mean, you could argue there are clear sub-groups of patients. But... yeh what the middle bit looks like is kind of different depending on their presentation. I mean you are using the same stuff. But, yeh</p> <p>It's quite dependent on more specific..?</p> <p>Yeh</p> <p>Okay, umm just going back a little bit to umm, you have in some ways covered this, but I will ask it specifically again.</p>	<p>Need for DS to be witnessed by others</p> <p>Value of having seizures in session</p> <p>Value of having trial structure</p> <p>Structure set useful frame</p> <p>Course of therapy varied</p> <p>Need for flexibility regarding content of middle sessions due to diversity</p>
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<p>What psychological processes did you think you were targeting, directly or indirectly in the intervention?</p> <p>Okay... well definitely umm... identifying, understanding, sitting with emotions that may be uncomfortable. Umm... that kind of emotional education, ummm reducing emotion avoidance. Umm and kind of educating people around their emotions. And people can have really umm, unhelpful ideas about their emotions, that they're dangerous, or that they're wrong in some way or that they're unacceptable. Umm... yeh so I think that's an important part of it</p> <p>How frequent would you say that was in those people that you have got there?</p> <p>Ummm... all of them. Even if it wasn't explicit.</p> <p>There was some emotional illiteracy...</p> <p>Yeh, yeh... Dissociation, I mean think it's a useful concept. It's very poorly defined, umm people are talking about different things when they are talking about dissociation. But in terms of the kind of, the model of overwhelming affect and cutting off from aspects of your experience. Ummm... and kind of emotional numbing. Umm... think is relevant definitely.</p> <p>Mmmhmm</p> <p>Umm... I guess, you know people talk about trauma a lot with dissociative seizures and ummm, for some people there is clear traumatic incidents. Ummm where they are directly relevant to somebody developing dissociative seizures. Whereas for others it's quite subtle, it's almost, it's not really trauma, it's small 'T' trauma. You would call it kind of parents being critical or ummm finding school very difficult or like that example I gave about [earlier specific example of rejection] ... being rejected, umm</p> <p>So kind of a traumatic history, as opposed to specific trauma</p> <p>Yeh I think the word trauma is problematic, because if you don't have a good understanding of mental health conditions the you kind of immediately jump to PTSD, and we're not talking about PTSD at all. Ummm... it's just more kind of how people, the experiences people have in their life and what they have taken on as beliefs about themselves and, yeh... what they carry with them that I think is a kind of vulnerability to developing dissociative seizures</p> <p>Okay, so we've got: dissociation, trauma, ummm, the other</p>	<p>Emotion tolerance/education important</p> <p>Emotions perceived as dangerous</p> <p>Difficulty with understanding, recognising and managing emotions present in all clients</p> <p>Value of dissociation concept</p> <p>Presence of trauma</p> <p>Small 't' trauma – traumatic upbringing</p> <p>Traumatic experiences lead to maladaptive self-beliefs in this population</p>
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<p>one you mentioned...</p> <p>Emotional processing, I guess some people might call it alexithymia. Which, yeh... difficulty labelling and recognising emotional states in yourself and others... I kind of prefer emotional processing, sort of difficulties. Think it's the best labelling. I guess alexithymia can be a helpful concept.</p> <p>Any others...</p> <p>Any others... beliefs about emotions... that's come up already. The, you know, the somatic experience of emotions is relevant, you know people being more prone to notice their bodies. Umm.. and, umm yeh paying attention to how people describe that. Ummm.. and noticing what they do in sessions as well</p> <p>Okay</p> <p>Yeh so 'I noticed you turned away then' or 'I noticed then that you clenched your fists then' or 'what do you think that's...'</p> <p>So the process of drawing their attention or...</p> <p>Yeh, and errm some people kind of, this errr, how do I say this. Kind of, not, not seeing the signs in their body as signs of emotion.</p> <p>Mmmhmm</p> <p>Yeh, yeh so again the misinterpretation of...</p> <p>But they're not subjectively always noticing that...</p> <p>Yeh not even necessarily conscious, yeh. Just this kind of... yeh and they'll often use sort of you know 'How are you feeling?' and they might say something really vague like 'stressed'.</p> <p>Okay</p> <p>Like 'Okay but what does that feel like?'</p> <p>Okay errmmm, again I hope you don't feel you are repeating yourself. But were there characteristics of clients that made it easier or harder for them to work with the treatment?</p> <p>Yeh... I mean doing homework is a problem for some people. Definitely.</p>	<p>Alexithymia present in clients</p> <p>Relationship between emotional difficulties and somatic pain</p> <p>Need to help clients recognise their own emotional processes</p> <p>Inability to recognise emotions</p> <p>Difficulty describing emotions</p> <p>Difficulty with completing homework</p>
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<p>Were there any typical explanations, reasons?</p> <p>Yeh, umm writing things down being difficult, or being embarrassed about their handwriting or ability to spell</p> <p>Okay</p> <p>Kind of making time for it. Ummm... yeh</p> <p>Were any of those, were you able to kind of overcome any of those things, or when you did try were there even any further problems when you did try to overcome those things</p> <p>Yeh I mean people's avoidance would obviously get in the way of some homework! Or people, very busy people treating sessions as kind of like 'I don't have to think about this any other time other than when I'm in this session'. Just sort of arrive and then kind of you know...</p> <p>So it's like an opportunity to deal with it and get it all out but they're not really think about it in terms of something that should be done outside the session?</p> <p>They're not really taking it through in their actual life. Yeh I mean that's not many people o be honest. But a couple of them were like that. Umm yeh, I mean the people were, where you couldn't really identify clear avoidances. That was hard sometimes to set homework. SO you would get to though diaries and focus on that a lot. But having the behavioural goals was sometimes quite difficult for people because they were working, they were seeing their family they were seeing their friends. They weren't really engaging in any kind of active avoidance that was to do with their dissociative seizures. They had kind of got past that point in a way. They might have done initially but they weren't doing it anymore</p> <p>Umm, okay, we've spoken about issues to address... yeh ummm could sessions ever become sidetracked or derailed by other issues. SO wondering where things like social issues, safeguarding, health-related concerns</p> <p>Yes, yes definitely. Ummm yeh I mean, just having a look at my list here. Yeh one person sort of developed quite significant other dissociations. [details omitted]Ummm and actually also yeh s/he became very very suicidal. SO then having to engage with local services. Yeh, you know sort of time being spent on risk management as opposed to the treatment. But other than that... Yeh considering, you know</p>	<p>tasks</p> <p>Self-consciousness regarding homework</p> <p>Avoidant behaviour disrupted homework</p> <p>Some clients too busy to do tasks</p> <p>Clear behavioural avoidances sometimes absent</p> <p>Some people living full, active lives</p> <p>Avoidance behaviours may have reduced over time while seizures remain</p> <p>Treatment could be disrupted by need to manage risk factors</p>
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<p>a group of, I mean actually someone I'm seeing in treatment at the moment, I think we have just done session four, she has a really complex [risk history]. But surprising, you know when I got the assessment session I thought 'oh dear how are we going to contain this,, and you now it's early days, but it's actually quite helpful having this very very structured, you know 'tjis is what we are focusing on, to help you cope with your dissociative seizures'. Keeping it quite focused on that, and luckily the avoidance, the 'panic-without-panic model is really relevant for her. I mean it's just spot on</p> <p>Okay</p> <p>SO it's working, it's you know, we're totally on track. We're not getting derailed because perhaps on appear we might think. 'Oh dear we're going to be dealing with risk issues every week'. But because s/he is involved in local services, so far...</p> <p>So sounds like in that case you are saying there is actually a lot of complexity, but actually this intervention has been a bit of a focus for her somehow?</p> <p>Yes, I am actually quite hopeful about the outcome. In terms of treating the dissociative seizures, they have lessened already. She has good understanding, we've got some good avoidance goals we are working on. So, no I think, you know it just sort of shows you that when you have got, when you have got a very clear kind of treatment approach, you can sort of focus even within this sort of complex presentation.</p> <p>Mmhmm, so complexity doesn't necessarily umm preclude this from being useful</p> <p>No, not at all, not at all. But again we come back to therapist skill. That, yeh, I do think you're working with very complex people. I do think you need to, yeh.</p> <p>Sure</p> <p>I don't think being a kind of newly qualified CBT therapist would manage it. I don't know if that's just being a bit egotistical, maybe I'm completely wrong. I'm sure the trial will show results either [laughing]</p> <p>Sure, no that's helpful thank you. And moving on to the final group of questions here. Umm this is, sort of with regards to the overall care pathway. SO we are thinking here about standardised medical care alongside CBT. So the bits that</p>	<p>Presence of risk and complexity</p> <p>Working effectively despite risk and complexity</p> <p>Structure useful despite complexity</p> <p>Importance of linking with local services where risk present</p> <p>Positive experience with complex clients</p> <p>Value of clear, structured approach with complex client</p> <p>Need for therapist skill to manage complexity</p> <p>Inappropriate for inexperienced therapists</p>
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<p>have been done by, as I understand it, the neurologist and the psychiatrist prior o you seeing them and maybe alongside you seeing them as well. What did you think about the care pathway, so kind of how it was joined up.</p> <p>Yeh... I think that works really Well. I suppose because of where I'm based it makes the most sense. You know we have close links with neurology. I'm in the same team as psychiatrists. SO I think it makes sense and it works well. But I guess maybe it doesn't work as well if you are in separate teams.</p> <p>45'18</p> <p>Okay</p> <p>Errrm yeh.</p> <p>And also errmm, how, when you encountered your clients the first time after that referral process, how errm how sort of 'primed' were they in terms of...</p> <p>Oh right, in terms of</p> <p>In terms of how the diagnosis had been presented to them</p> <p>Yes generally... very well. I mean only one person has dropped out from the people I have seen because of questioning the diagnosis. So generally engaged very well with the communication of the the diagnosis. Even if there were some reservations, still engaged in treatment</p> <p>And do you feel that they understood the diagnosis on the whole or..</p> <p>...(thinking) Yes I think so. I mean it's difficult to know because obviously I would go over it again. SO difficult to know how much they had taken in before. But they certainly were familiar with what I was talking about so it wasn;t kind of new to them</p> <p>Okay</p> <p>Just reiteration</p> <p>And how, what did you think the diagnosis did mean to them. Like if you were to ask them what their diagnosis meant what would they way?</p> <p>For some it was a relief – you know that it wasn't epilepsy. For some it was a bit frustrating because, you know, how do</p>	<p>Good working relationship with neurologist</p> <p>Value of being located near neurology</p> <p>Clients well prepared by SMC</p> <p>Some clients not entirely convinced by diagnosis</p> <p>Unclear what level of understanding clients had of diagnosis at presentation</p> <p>Likely some information retained from SMC</p> <p>Relief from diagnosis</p> <p>Frustration from</p>
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<p>you explain it to people... There's, you know, I guess it just wasn't really that important to them. It was more, they were really pleased to be seeing a psychologist and having treatment. Perhaps they weren't as, perhaps by that point they weren't as pre-occupied with the diagnosis. I think it really helps with the treatment to have that kind of staged approach. You know they have seen an experienced neurologist, they have seen an experienced neuropsychiatrist and, you know they have seen a therapist. And I think it gives huge validity to the diagnosis and umm by the time they see you it's kind of...</p> <p>SO they're quite accepting of it by that stage on the whole?</p> <p>Yes in my experience they were. I mean, yeah, yeah</p> <p>Errmmm and did the clients ever sort of discuss their experiences of medical care in your sessions?</p> <p>Errr very rarely, errmmm, sometimes it would be a comment about 'didn't have much time to talk' or it might stray into medication queries, in which case I might get back to them once I had spoken to the psychiatrist. Errmm... yeh not much, no.</p> <p>Okay, thank you. I realise there are some things I should have asked earlier on that we have sort of added on here. Specifically in relation to the training you have had, which I realise was some time ago now.</p> <p>..long time ago yeh</p> <p>Quite a long time ago now. Just from your, from the memories that you do have, what, do you feel that you were sort of well equipped by it to do this intervention, or did you feel that you weren't well-equipped by it</p> <p>It's a really long time ago! It was three days wasn't it? Yeh it was very useful, it was difficult because I went to the training just when I had started in this job. So I had very limited, I had one case of dissociative seizures before working here so... wasn't experienced at all at working with them. So me as a novice, I think it was very useful to have the kind of, the information from neurology and experienced psychologists. Errmm.. I don't know whether I had thought differently about it if I went on now. I don't think it can hurt can it. I guess the difficulty is when you are working with people with dissociative seizures is you can't just cookie</p>	<p>diagnosis</p> <p>Clients valued psychological input</p> <p>Value of the ordering of multidisciplinary contacts</p> <p>Value of seeing experienced SMC clinicians</p> <p>Clients typically accepting of diagnosis by time of therapy presentation</p> <p>Insufficient time with SMC clinicians</p> <p>Limited experience of DS prior to trial</p> <p>Value of receiving instruction from specialists</p> <p>Need for individualised intervention</p>
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<p>cutter out a treatment, so that's a challenge in the training.</p> <p>Okay</p> <p>Supervision is really important, yeh. I would say that the supervision was, has been kind of, not that the training wasn't good, it was good, but I would say that the supervision has been much more important in terms of maintaining fidelity to the model, answering questions and sort of trouble shooting difficulties. Because you kind of need to do it to yeh... you know learning in theory it's not really the same as learning in doing is it?</p> <p>So the supervision has given you the opportunity to talk through how these specific things relate to the model in the particular things you are doing</p> <p>Yeh exactly where particular things come up in cases that you are seeing</p> <p>Okay</p> <p>Umm, treatment planning, problems that have come up,</p> <p>I'm just going to dole check now that there's nothing that I should have really asked you that I haven't asked you.</p> <p>Ummm... [checking]. Oh I skipped this one out, ummm.. the booklet for clients, I don't think I asked you about this, were there any particular chapters in the clients' booklet that you found more or less useful if you were directing them to that?</p> <p>Errrrmmm...</p> <p>Actually sorry, and <i>did</i> you direct teh to the book?</p> <p>Yes, I always directed them to the reading, ummm... Yeh I don't, I think they were all useful. None were not useful.</p> <p>Ummm... in terms of more useful, ummm, oh the applied tension technique. Don't find that useful for anybody. That could easily be left out. Umm... but yeh the chapter on grounding and distraction strategies, the guide for other people, that's nice. Umm... yeh thought challenging is good. You know the trauma chapter is good at kind of naming what might be missing, in terms of for some people. Yeh I mean I think generally it's good, you know in terms of creating a manual that's good for everybody I think it's good.</p> <p>Did you, did any clients kind of have any feedback? Were ther any occasion where they might have mentioned...</p>	<p>Supervision encouraged adherence to the model</p> <p>Supervision clarified application of model to specific cases</p> <p>Positive comments regarding all chapters in patients' manual</p> <p>Applied tension technique not useful</p> <p>Grounding techniques and distraction useful</p> <p>Trauma chapter valuable</p>
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<p>No</p> <p>Just checking</p> <p>No, no</p> <p>I think that's probably everything, I'll just pop these off</p> <p>[end of interview]</p>	
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Appendix K:
Example pages of transcripts coded by second coder (JR)

her assumptions in social situations. I would say that... I don't know what the data says, but that it would probably help to keep her, I mean she was dissociative seizure free at the end of treatment and I think that social anxiety work may have helped to keep her well. You can't sort of.. yeh it's that kind of balance of 'okay we're treating dissociative seizures' and with some of them by session 5 or 6 they have stopped. And then what you are left with is 'Okay what might be going on alongside this, underneath this, that might be driving it. So often: anxiety or sort of social defectiveness is in, in my experience of this caseload... ermm	Social anxiety driving seizures
Okay so scope to touch on those things or to provide avenues to explore other areas	
I think if it was strictly right ermm... you're panicking about the feelings of having the dissociative seizure and that's the problem. You know we need to test out those assumptions and we need to do graded exposure to reduce your avoidance. If it was only that, I don't think you can apply that to everybody.	
Okay	
I think it's a good model for a lot of people. But I don't think it's totally applicable to everyone	Panic model no fit for all
Okay, ermm... moving on to ermm... sort of a few clinical details. So what would you say about your, your clients' ability to relate the CBT model to their difficulties, and how satisfying or meaningful did they tend to find this as an explanation for their problem?	
Yeh I think the CBT model generally is very well understood by patients. Are you talking about the panic without panic model?	CBT model understood well
I suppose the model as it's presented in here, which is quiet focused on that, but includes other aspects...	
Yeh, well I think the act of breaking down into thoughts, feelings, behaviours, physical sensations, that in any given situation this is going on for you is really helpful for these patients who may particularly be people who struggle to identify their emotions. So I would often give people a feelings wheel, a list of 'feelings words' to help them think 'what is this I'm feeling?'. Because that sort of emotional education.. I think the CBT model of intervention is very good at delivering that in a way that's not, in a way that is quite palatable, that makes sense to people	"Feelings wheel" as emotional education
And they were able to relate that to their difficulties and current situations?	
Definitely, you know that the way they think about something affects the way they feel, or, the way they act in a situation affects the way they feel, and the way they think you know definitely... that wasn't a problem for anybody	CBT model understood well
Okay	
But specifically the panic without panic model... yeh... hmm... the model of dissociation was more.. the idea that it was too much and they were dissociating and that that may have been the reason for them starting. Most people could definitely relate to that. You know – stressful events, or just the sort of the emotional processing style. Ermm.. the reasons for it continuing, you could kind of identify that for some people it was always stress triggering them off. For others they would be quite relaxed - identifying it as a habitual response to similar feelings in the body.	Stress as trigger for DS

definitely.	
Mmmhmm	
Umm... I guess, you know people talk about trauma a lot with dissociative seizures and ummm, for some people there is clear traumatic incidents. Ummm where they are directly relevant to somebody developing dissociative seizures. Whereas for others it's quite subtle, it's almost, it's not really trauma, it's small 'T' trauma. You would call it kind of parents being critical or ummm finding school very difficult or like that example I gave about [earlier specific example of rejection] ... being rejected, umm	Trauma versus small "T" trauma
So kind of a traumatic history, as opposed to specific trauma	
Yeh I think the word trauma is problematic, because if you don't have a good understanding of mental health conditions the you kind of immediately jump to PTSD, and we're not talking about PTSD at all. Ummm... it's just more kind of how people, the experiences people have in their life and what they have taken on as beliefs about themselves and, yeh... what they carry with them that I think is a kind of vulnerability to developing dissociative seizures	Specific trauma versus bad experiences Beliefs about themselves lead to vulnerability
Okay, so we've got: dissociation, trauma, ummm, the other one you mentioned...	
Emotional processing, I guess some people might call it alexithymia. Which, yeh... difficulty labelling and recognising emotional states in yourself and others... I kind of prefer emotional processing, sort of difficulties. Think it's the best labelling. I guess alexithymia can be a helpful concept.	Emotional processing difficulties
Any others...	
Any others... beliefs about emotions... that's come up already. The, you know, the somatic experience of emotions is relevant, you know people being more prone to notice their bodies. Umm.. and, umm yeh paying attention to how people describe that. Ummm.. and noticing what they do in sessions as well	Somatic response/negative beliefs about emotions
Okay	
Yeh so 'I noticed you turned away then' or 'I noticed then that you clenched your fists then' or 'what do you think that's'...	
So the process of drawing their attention or...	
Yeh, and erm some people kind of, this errr, how do I say this. Kind of, not, not seeing the signs in their body as signs of emotion.	
Mmmhmm	
Yeh, yeh so again the misinterpretation of...	
But they're not subjectively always noticing that...	
Yeh not even necessarily conscious, yeh. Just this kind of... yeh and they'll often use sort of you know 'How are you feeling?' and they might say something really vague like 'stressed'.	
Okay	
Like 'Okay but what does that feel like?'	
Okay errmmm, again I hope you don't feel you are repeating yourself. But were there characteristics of clients that made it easier or harder for them to work with the treatment?	
Yeh... I mean doing homework is a problem for some people. Definitely.	Homework as problem
Were there any typical explanations, reasons?	
Yeh, umm writing things down being difficult, or being embarrassed	Embarrassment about

Appendix L:

Examples of loosely grouped coding labels from initial coding stage

Flexibility & Structure-related free codes

excessive adherence to structure bad for engagement
 sense of flexibility increasing over course of trial
 good level of flexibility
 importance of sticking to model while not being too dogmatic
 lack of flexibility
 needs more flexibility
 possibility for flexibility
 sense of constraint or dislike of constraint
 some clients completed earlier
 need for flexibility in middle sessions
 supervision permitted or encouraged flexibility
 need for flexibility in number of sessions & use of sessions
 structure set useful frame
 good ordering
 issues with pacing
 need for flexible re-ordering
 not enough time-squeezing too much in
 pacing appropriate for some, not others
 suggestions for changing structure
 value and usefulness of having structure of intervention
 value of returning to techniques later in intervention
 well-balanced intervention
 value of having structure
 sense of constraint

Co-morbidity & complexity-related free codes

attachment-related issues
 difficulty trusting people
 difficulty with emotions
 emotional instability
 seizures as communication
 presence of subgroups
 variety in levels of complexity
 interpersonal difficulties
 misinterpretation or too much attention to bodily cues
 presence of dissociation
 somatization tendency
 comorbidities were common
 complexity of clients
 other mental health input
 multiple functional symptoms
 need for complex intervention
 need for highly skilled practitioners
 need for experienced clinicians
 other physical health problems
 presence of depression
 presence of emotionally unstable personality disorder
 presence of epilepsy complicated treatment
 presence of health anxiety
 presence of OCD
 presence of sustained stress
 presence of social anxiety/defectiveness belief
 ability of people with trauma to benefit from intervention
 absence of trauma
 client apprehensive about approaching trauma
 ongoing trauma
 presence of trauma
 problems of not working with trauma

Appendix M:
Working analytical framework with codebook

Themes	Subthemes	Codes
Complexity of clients	Physical health difficulties	Presence of physical health difficulties Physical health difficulties complicating treatment Concerns regarding unidentified health problems Presence of epilepsy disrupting treatment
	Mental Health difficulties	Difficulties trusting or interacting with others Significant depression present in clients Presence of trauma Obsessive compulsive disorder present Presence of social anxiety or perceived social defectiveness Excessive attention to bodily cues Other mental health difficulties
	Need for clinician skill to manage complexity	Need for suitably qualified and experienced clinicians Successful intervention not achievable through following simple protocol
	Other complicating factors	Significant risk issues disrupting treatment
Comments on intervention components	Family involvement	Value of involving family Importance of family view on diagnosis Family chapter in manual of significant value Need for family members to adjust to approach Possible over-emphasis on family involvement
	Seizure control techniques	Value of seizure control techniques

		Value of patients' chapter on seizure control techniques Techniques delay seizures but do not stop them
	Graded exposure and its applicability	Value of graded exposure Limitations of graded exposure Presence of avoidance and safety behaviours Presence of emotional avoidance, sometimes without behavioural avoidance
Flexibility and structure	Flexibility possible	Good level of flexibility perceived Increasing sense of flexibility over time Supervision permitted or encouraged flexibility
	Pacing and ordering	Squeezing too much in Insufficient time for assessment and formulation Sensible ordering of intervention
	Benefits of having structure	Structure acted as a 'touchstone' Value of structure for clinicians new to the client group
	Insufficient flexibility	Need for greater flexibility and prioritisation Therapists feeling constrained by protocol Need to strike balance between flexibility and dogmatism
Adequacy of intervention		Ability of people with trauma to benefit from intervention
	Usefulness of intervention despite complexity	Ability of people with significant risk histories to benefit from intervention
	Intervention inadequate	Need for further therapy after trial Limited ability to work with trauma
Formulation		Need for intervention to be formulation driven

		<p>Significant insights from formulation</p> <p>Specific value of CBT approach to formulation</p> <p>Value of tailoring to specific client background and history</p>
Views on standardised medical care	Perceived level of diagnostic understanding in clients following contact with neurologist and psychiatrist	<p>Good level of diagnostic understanding at presentation</p> <p>Limited level of understanding at presentation</p> <p>Moderate level of understanding at presentation</p> <p>Impact of diagnostic understanding on subsequent therapy</p>
	Clients reports of experiences with SMC clinicians	<p>Positive experiences with psychiatrist</p> <p>Clients reported good amount of time spent by SMC clinicians</p> <p>Clients reported insufficient time with psychiatrist</p>
	Working relationship with SMC	<p>Value of close relationship with neurologist</p> <p>Value of close relationship with psychiatrist</p> <p>Lack of close working relationship with SMC colleagues</p>
	Other	<p>Value of standardising medical approach</p> <p>Perceived superiority of SMC compared with medical care outside trial</p>

Appendix N:
Example of Data charted into framework matrix

Interview	Differing applicability of intervention components (cont.)				Flexibility and structure			
	Graded exposure and its applicability				Flexibility possible		Pacing and ordering	
	Value of graded exposure	Presence of avoidance and safety behaviours	Limitations of graded exposure	Presence of emotional avoidance, sometimes without behavioural avoidance	Good level of flexibility perceived	Increasing sense of flexibility over time	Supervision permitted or encouraged flexibility	Squeezing too much in
1		Yeh, oh yeh there's huge amounts of avoidance. There's huge amounts of safety behaviours.	I would say that the avoidance was really sort of an emotional avoidance. In which case being in the therapy was sort of facing that errm. You can't really do a graded exposure	I would say that the avoidance was really sort of an emotional avoidance		T: Yeh, you're just far more familiar with the literature and the pack and yeh? MW: So it runs a bit smoother in some ways? T: Yeh I think you've just got the confidence that you know, to kind of have a bit more flexibility	Yeh I think [supervising therapist] was saying there was more flexibility	

<p>2</p>	<p>Where it was relevant graded exposure was perfect.</p>		<p>Where it was relevant graded exposure was perfect. But there were a few cases where it really, it wasn't really that level of avoidance</p>		<p>nice to have the structure, umm the therapy in terms of the outline of the sessions, but also within that the flexibility to do what I would normally do in CBT which is an individual formulation and guiding treatment by the patient rather than specifically strict manual</p>			
<p>3</p>	<p>Well I've only had three. But then the other person... has done quite well with the graded exposure</p>		<p>Certainly in one of the cases the graded exposure aspect of the work was very difficult for the person to do</p>		<p>But it was, obviously it was flexible enough that you could take it into account in the kind of formulation and their understanding of why they've got the seizures.</p>			

<p>4</p>	<p>They can see that they can engage in thinking other than about the seizures and switch that that pattern of behaviour whereas they would usually sort of avoid</p>			<p>I suppose, emotional avoidance is something that comes up a lot of the time as well. People will often sort of say that they don't get anxious they don't get depressed, they just cope they just get on with it</p>	<p>I think it is just a structure, I guess it has that flexibility I guess that we can, particularly in the latter stages to sort of be more idiosyncratic.</p>			<p>the sessions can be quite packed out. I can't remember offhand, I think it was session 4 or 5 where there's, the list is like, you know we do one of the seizure control techniques, seeing the family and we talk about trauma and how it relates to the seizures and then we do something else</p>
<p>5</p>		<p>Oh fear-avoidance absolutely. That's central to all of them</p>		<p>I've had a lot of people who are absolutely emotionally avoidant. Errm and I call them 'repressors' – all their emotions have been repressed.</p>	<p>So yeh just get the stuff that you need to get done done and then have a bit of leeway in the latter half of the sessions for it to be very – because you know people might have social anxieties, they might have other kinds of issues that are specific stuff that needs to be worked on</p>	<p>after time I was like, so I would choose 'lets try this first, lets try that first'. SO I would try to kind of like streamline it so that it wasn't so pressured. But I think that came with experience of using the manual</p>		<p>SO I felt a bit pressured – now whether that then got, whether they then felt really pressured – I tried really hard not to, but I think that might be one of the things that they felt 'there's a lot of stuff here'</p>

<p>6</p>		<p>MW: I suppose a lot of this, the original model was focused on the fear-avoidance model. And was that something that you felt featured in many of your clients? P: Oh yeh definitely, definitely.</p>		<p>And because the people that I've seen... emotional exposure is the hardest, the most unbearable I guess that's kind of why I take the approach of prioritizing that in a way.</p>		<p>I think maybe at the start I followed it more religiously but then I found that ot was like trying to force somebody into a box. So I stepped back from that and used the manual as something that was informing my approach and that's sort of how it is now.</p>	<p>I think for me I very much focused on how [supervisor] said it's formulation driven. So I used the manual in a way that was applicable to whoever it w as that I was seeing</p>	
<p>7</p>	<p>I think once they started to do some behavioural stuff and, and, and if they ...went out and did something and found that their anxiety went down, that was a 'lightbulb moment'</p>	<p>Yeah, they had fear of something, even if it was going outside. Even if they said they didn't, they did have something, even if it was just a lesser extent. They realised when we went through things that they had not been, you know, whatever, meeting people for, well it had been so long that they actually thought this was normal.</p>					<p>When we took any pat...clients to supervision or anything, you know, it felt less strict. You knowyou were doing all the things, but actually it wasn't, you know, you..I, I felt I could be very flexible</p>	

8		<p>really there was very limited activity that they did, most of them. Errm so certainly avoidance of going out avoidance of socializing</p>		<p>P: Avoidance was a big one for all of them I guess. MW: Avoidance of? P: Emotions, and fear over - panic over any kind of physical sensations.</p>			<p>Yeh I mean I found that in the supervision and the training they said that you can be flexible.</p>	<p>I felt that , and this might be just some of the patients that I saw, that, that we can only have a certain amount of sessions, which is fair enough. But the – so there are aspects of the manual you wouldn't have much time to do.</p>
9		<p>MW I was wondering whether fear-avoidance seemed to feature in your clients' presentations at all? P: yeh, I'd say errm for nearly everyone.</p>	<p>There was one person where it wasn't a feature and that was the person I was just talking about. I don't think s/he really avoided</p>	<p>Lots of, I guess, avoidance of internal stuff, emotional avoidance</p>			<p>MW: What message did you feel you were given in supervision about that? T:Just that we could be more creative with it. Because I think it would be impossible to kind of put everything that's in there into 12 sessions – there's loads in there!</p>	

<p>10</p>		<p>I mean there was avoidance for some people. I think that there's – I think fear is very present for everybody who has seizures. I think that's the underlying commonality</p>	<p>I had quite a few patients for whom avoidance wasn't an issue.</p>	<p>MW: Some of the other therapists spoke about emotional avoidance. Was that a feature in some of the... P:Yeh, definitely, yeh. But again I would say emotional avoidance generally, not just the emotional avoidance of having a seizure</p>				
<p>11</p>	<p>The fact that s/he was even coming here, s/he actually started coming here by herself, that was huge, you know, from like not leaving the house</p>	<p>SO yeh quite a lot of avoidance, to the, you know, the extent that his/her life was really restricted in the end and everyone else was doing things for him/her</p>			<p>I felt that it was sort of flexible enough within, you know, the bigger CBT framework to work with cases and maybe adapt it slightly</p>			

<p>12</p>		<p>so there was obviously anxiety avoidance, that was part of it, so avoidance of anxiety-provoking situations, and trying to get people to expose themselves to anxiety-provoking situations, to be more active, that was part of it</p>		<p>I think definitely the role of emotions and avoidance of emotions I think made sense to them in this particular case.</p>	<p>It was quite flexible, the approach in some ways, erm, it wasn't too prescriptive about what you might do</p>			
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Appendix O

Notes for contributors for 'Seizure' – abridged guidelines downloaded from <https://www.elsevier.com/journals/seizure-european-journal-of-epilepsy/1059-1311/guide-for-authors>

**SEIZURE - EUROPEAN JOURNAL OF EPILEPSY****NEW SUBMISSIONS**

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.

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There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

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If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

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This journal operates a single blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. [More information on types of peer review.](#)

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Regardless of the file format of the original submission, at revision you must provide us with an editable file of the entire article. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the [Guide to Publishing with Elsevier](#)). See also the section on Electronic artwork.

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State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

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Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized, and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

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Results should be clear and concise.

Only in case of short communications, the results and discussion sections may be combined. Results should usually be presented in graphic or tabular form, rather than discursively. There should be no duplication in text, tables and figures. Experimental conclusions should normally be based on adequate numbers of observations with statistical analysis of variance and the significance of differences. The number of individual values represented by a mean should be indicated.

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This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Speculative discussion is not discouraged, but the speculation should be based on the data presented and identified as such.

In most cases a discussion of the limitations is appropriate and should be included in this section of the manuscript.

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The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

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If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

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- **Title.** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
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A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Abstracts for regular articles and short communications should be structured, using the subheadings purpose, methods, results, conclusion. For reviews, the abstract does not need to follow this structure. They should be no longer than 250 words. Case reports (Clinical Letters) do not need to be preceded by an abstract.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using British spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

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Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

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Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. *J Sci Commun* 2010;163:51–9.

Reference to a book:

[2] Strunk Jr W, White EB. *The elements of style*. 4th ed. New York: Longman; 2000.

Reference to a chapter in an edited book:

[3] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. *Introduction to the electronic age*, New York: E-Publishing Inc; 2009, p. 281–304.

Reference to a website:

[4] Cancer Research UK. Cancer statistics reports for the UK, <http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/>; 2003 [accessed 13 March 2003].

Reference to a dataset:

[dataset] [5] Oguro M, Imahiro S, Saito S, Nakashizuka T. Mortality data for Japanese oak wilt disease and surrounding forest compositions, Mendeley Data, v1; 2015.

<https://doi.org/10.17632/xwj98nb39r.1>.

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (*J Am Med Assoc* 1997;277:927–34) (see also [Samples of Formatted References](#)).

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