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## Neurologists' experiences of participating in the CODES study—A multicentre randomised controlled trial comparing cognitive behavioural therapy vs standardised medical care for dissociative seizures

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### ABSTRACT

**Purpose:** We investigated neurologists' experience of participating in the large CODES trial involving around 900 adults with dissociative seizures which subsequently evaluated the effectiveness of tailored cognitive behavioural therapy (CBT) plus standardised medical care versus standardised medical care alone in 368 patients with dissociative seizures.

**Method:** We asked all neurologists referring patients with dissociative seizures to the CODES study to complete a 43-item online survey. This examined neurologists' (i) demographics, (ii) knowledge of dissociative seizures before and after their involvement in the CODES trial, (iii) clinical practice before, during and since their involvement, and (iv) their experience of the CODES trial.

**Results:** Forty-three (51%) neurologists completed the questionnaire. Only about half of neurologists could make referrals to psychological intervention specific for dissociative seizures before and after the trial. One-third of doctors reported having changed their referral practice following their involvement. The majority (> 69%) agreed that patient satisfaction with different aspects of the trial was very high, and 83.7% thought that it was easy to recruit patients for the study. Over 90% agreed they would like the treatment pathway to continue. Respondents found different elements of the trial useful, in particular, the patient factsheet booklet (98%), diagnosis communication advice (93%) and the CBT package (93%).

**Conclusions:** Neurologists participating in CODES generally found it easy to recruit patients and perceived patient satisfaction as very high. However, 46.5% of neurologists could not offer psychotherapy once the trial had finished, suggesting that problems with lack of access to psychological treatment for dissociative seizures persist.

### 1. Introduction

Dissociative seizures—also referred to as psychogenic non-epileptic seizures—account for about 20% of referrals to seizure clinics [1]. Traditionally, neurologists have viewed their role as limited to the diagnosis of dissociative seizures rather than the treatment of this disorder [2]. While there is currently no clear evidence base, expert opinion has favoured psychotherapeutic treatments [3], although most patients perceive their dissociative seizures as a problem which is largely “physical” [4]. Consequently, many patients resist neurologists' proposal to pursue a psychotherapeutic treatment approach [5,6], re-

enforcing the views of health professionals that patients with dissociative seizures are particularly challenging or “difficult” [7].

We took advantage of the CODES trial on dissociative seizures to explore neurologists' attitudes and experiences of treating patients with the condition in the context of this clinical study. Whilst the CODES trial primarily explored the benefit of adding cognitive behavioural therapy to standardised medical care, participation in recruitment made it necessary for neurologists to be more firmly involved in a treatment pathway for patients with dissociative seizures: They had to communicate the diagnosis in a prescribed fashion, refer patients to participating psychiatrists, and were encouraged to offer neurological

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follow-up as part of the standardised care package rather than to discharge them at the point of diagnosis [8].

The aim of the present study was to investigate neurologists' experience with this deeper involvement in the treatment of dissociative seizures, to explore their knowledge of dissociative seizures and clinical practice for patients with the condition before and since their involvement in the trial, as well as their opinions on the utility of the various components of the CODES intervention.

## 2. Methods

The CODES trial is a United Kingdom (UK)-based multicentre, pragmatic, parallel group randomised controlled trial designed to evaluate the clinical and cost-effectiveness of specifically tailored cognitive behavioural therapy (CBT) plus standardised medical care versus standardised medical care alone for adults with dissociative seizures. In total, neurologists identified 901 patients with dissociative seizures as possible candidates for the CODES study over a 29-month period; of these 698 were recruited to the first stage of the study. Ultimately, 368 patients entered one of the two treatment arms after reassessment for suitability for randomisation by a psychiatrist. Self-report measures were completed at baseline, 6 and 12 months post-randomisation. The protocol and statistical analysis plan for the trial have been published elsewhere [8,9].

### 2.1. Neurologists' role in the CODES trial

In the CODES trial, standardised medical care first involved neurologists making an assessment to determine the nature of the patients' seizures. Neurologists were encouraged to follow their usual diagnostic process (i.e. patient history, witness history, physical assessment, brain imaging if appropriate and where possible, video-electroencephalography (video-EEG)). If the diagnosis of dissociative seizures was not supported by the video-EEG recording of a typical seizure, the evidential basis of the diagnosis was reviewed by an independent neurologist who was given access to all relevant clinical data. Neurologists participating in CODES also had to explain the diagnosis to potential participants. Their explanation of dissociative seizures was expected to cover the same topics as the factsheet given to patients after their appointment (see Neurology leaflet at <http://www.codestrial.org/information-booklets/4579871164>): i) what dissociative seizures are, how the tests confirm the diagnosis, that the episodes are genuine, the disorder is common and treatable; ii) the underlying mechanism of dissociative seizures specific to the presenting symptoms and experiences; and iii) the rationale for making a referral to a psychiatrist. Neurologists had to give all potential participants an information sheet describing the trial and to take consent from all potential participants to pass on their contact details to research staff. Patients were then contacted by CODES researchers who offered more information about the study and obtained written consent to the initial observational part of the study. Neurologists had to refer all patients who had agreed to take part in the CODES trial to a participating psychiatrist who was expected to contribute to patients' further standardised care as well as assessing their suitability for entry into the second phase of CODES in which around 53% of all participants were randomised to standardised care with or without additional CBT. Neurologists were encouraged to offer CODES patients at least one follow-up visit in the neurology department [8]. Participant information sheets for both phases of the CODES trial are found in supplementary files 1 and 2.

### 2.2. Recruitment

Eighty-four neurologists/epilepsy specialists were invited to take part in the current study via email (all of the 91 neurologists/epilepsy specialists involved in the CODES trial were initially contacted; however, the email addresses of seven were no longer functioning). We used

an online survey tool (Bristol Online Survey Tool) to distribute a purpose-designed, 43-item questionnaire (see supplementary file 3). A reminder to complete the questionnaire was sent to all neurologists two weeks after the initial invitation. All data were provided anonymously; no personal identifiers were gathered.

### 2.3. Questionnaire (see supplementary file 3)

The questionnaire was created by all co-authors. The questions explored: (i) respondents' demographics (age, gender, current role, years of clinical experience in neurology, and number of patients with dissociative seizures diagnosed per month and under their current care – 6-items); (ii) knowledge of dissociative seizures and treatments before and after their involvement in the CODES trial (4-items); (iii) clinical practice before, during and since their involvement in the trial (22-items); and (iv) experience of using CODES-related components (11-items).

Qualitative (i.e. open-ended questions) and quantitative data (i.e. Likert scales with multiple options – 5 = Strongly Agree, 4 = Agree, 3 = Neither Agree nor Disagree, 2 = Disagree, 1 = Strongly Disagree) collection methods were used.

### 2.4. Data analysis

All data were exported to an Excel datasheet. For quantitative data, descriptive statistics were used (M = median, IQR = interquartile range). To compare self-report scores before and after involvement in the CODES trial, because the data were ordinal, the Wilcoxon signed ranks test was used. An alpha value of 0.05 was used for all statistical analysis. Data was analysed using SPSS 24. For qualitative data, text was grouped thematically.

## 3. Results

### 3.1. Respondents' demographics

Overall, 43/84 (51%) participating neurologists completed the questionnaire. Forty were consultant neurologists. Sixty percent were male, 82% were aged between 41–60 years. Respondents had a median of 18 years (IQR = 9) of experience in neurology. They estimated the median number of patients with dissociative seizures they typically diagnosed as 3 per month (IQR = 3) and the median number of patients with dissociative seizures under their care at any one time as 20 (IQR = 40.5).

### 3.2. Knowledge of dissociative seizures

Doctors self-reported a good level of knowledge of dissociative seizures (i.e. aetiology, diagnosis, treatment, management and prognosis) before their involvement in the CODES study (M = 4, IQR = 1), which did not increase significantly through their involvement in the trial overall (M = 5 IQR = 1,  $p = 0.76$ ). Similarly, respondents reported having a good level of knowledge of how psychological intervention may help patients with dissociative seizures before (M = 4, IQR = 1) and after the trial (M = 4, IQR = 1,  $p = 0.67$ ).

### 3.3. Clinical practice for dissociative seizures

Doctors reported that they already felt confident overall when managing a patient with dissociative seizures before the trial (M = 4, IQR = 2). Their rating did not change as a result of their involvement in the CODES study (M = 4, IQR = 1,  $p = 0.1$ ). Fourteen doctors reported that, while taking part, they were more likely to consider dissociative seizures as a potential diagnosis at an earlier stage than they might have previously done (M = 3, IQR = 2).

About half (53.5%) of the respondents reported having personally

**Table 1**

Referral practice before involvement in the CODES trial (n.b. respondents could endorse multiple response options).

Practice	n
I referred patients with dissociative seizures to a psychiatrist / neuropsychiatrist/ neuropsychologist so that they could consider referring the patient for psychological intervention	26
I recommended to the General Practitioner that the patient with dissociative seizures should be referred to psychological intervention	15
I referred patients directly to psychological intervention specific for dissociative seizures	13
I could not refer patients to psychological intervention specific for dissociative seizures	10
I referred patients with dissociative seizures directly to psychological intervention	7
I recommended to patients with dissociative seizures that they should self-refer to psychological intervention	5
I did not refer patients with dissociative seizures to psychological intervention	2

been able to refer patients directly for psychological intervention specifically for dissociative seizures before the trial (i.e. to a specialist who knew about the condition and could provide effective treatment). This figure did not change once CODES had finished. Service availability was important; doctors who had access to psychological intervention specific for dissociative seizures before the trial started estimated that they referred an average of 78% of their patients. The equivalent estimate from those unable to refer patients directly was 12%. One respondent explained: “We didn’t have a specific service so I mostly muddled along on my own apart from some [patients] who I sent to Liaison Psychiatry or psychologists in other Trusts.”

As would be expected, before CODES, doctors differed in their referral practice (Table 1). The majority referred patients with dissociative seizures to psychological intervention directly or referred patients to another professional who might then make a referral for psychological intervention.

Around one third of neurologists explained that participating in the CODES study had changed their practice in relation to referring patients for psychological intervention. This included: more, earlier or direct referral; and the establishment of a dissociative seizures pathway within their organisation directly “on the back of the CODES study”. Some of the doctors who had not changed their practice explained that they already had a “very well developed local specialised psychotherapy service [for dissociative seizures]” or they “still can’t refer to psychotherapy [for dissociative seizures]” suggesting that they were unable to change their practice once the study had ended. One doctor reported that his/her referral practice had not changed but “the time [for patients] to be seen is getting longer... By highlighting the diagnosis to other clinicians [and therefore increasing the number of patients being diagnosed with the condition] yet not increasing resources to deal with them, my patients now have to wait even longer to be seen”. The ability to refer patients who lived outside of the practice area to psychological intervention during the trial was also a benefit: “During the course of the study I was able to refer patients to our psychotherapy programme if they had been referred from out of area. Before and since CODES I have not been able to do this”.

Only 16% of respondents indicated that their participation in the CODES study had changed their referral practices to psychiatrists/neuropsychiatrists. The majority of doctors agreed with the involvement of psychiatry for all patients with dissociative seizures before and after their involvement in the CODES study ( $M = 4$  IQR = 2,  $M = 4$ , IQR = 1,  $p = 0.1$ ). Having said that, before their involvement in CODES, only 55% ( $M = 60$ , IQR = 85) of the neurologists referred patients with dissociative seizures to a psychiatrist/ neuropsychiatrist. For some, this seemed to be because of availability: “There are no psychiatrists interested in dissociative seizures locally.”

Doctors were asked to report their usual approach to following up patients with dissociative seizures before, during and since their involvement in the CODES study (Table 2). While at a group level, involvement in the CODES study did not seem to change follow-up practice, 26% of doctors explained that the study had changed their practice in relation to dissociative seizures in other ways. Common changes made were: holding more structured or detailed discussions

with the patient (“I have seen a number of success stories and this has changed my approach to communicating and referrals”), greater signposting and information provision, using the CODES factsheet booklet, making direct referrals for psychological intervention, and making more referrals to other professionals.

While respondents did not report feeling more confident in managing patients with dissociative seizures overall, some doctors did express greater confidence in particular areas, for instance, saying that they felt more confident when exploring factors associated with the cause of dissociative seizures with the patient, and having gained more confidence in making and communicating the diagnosis without stigma.

### 3.4. CODES trial-related elements

Over 69% of doctors agreed that patient satisfaction for the psychiatric care and CBT developed for the CODES study was ‘very good’ (Table 3). Overall, 90% indicated they would like the pathway developed for the CODES study patients to continue within their service. Some data challenged the negative stereotypes commonly held about consulting with and treating patients with dissociative seizures; the vast majority (83.7%) of neurologists agreed that they found it easy to recruit patients with dissociative seizures to the trial and that patients appeared satisfied by being in the trial (> 69%). That said, keeping patients with dissociative seizures engaged was more commonly associated with ambivalence (34.9% neither agreed or disagreed), suggesting an acknowledgement of the difficulty maintaining some patients’ engagement.

We asked doctors how useful they found different elements of the CODES care pathway (Table 4). The majority found all resources ‘very’ or ‘extremely’ useful, particularly relating to CBT for those who received it (> 85% of doctors).

Overall, 91% of doctors agreed that they would like to continue to use the factsheet/ booklet on dissociative seizures with future patients (0% of doctors disagreed) – one respondent explained: “I found the online information and booklets to be extremely useful and often this in itself would be of therapeutic benefit”. Moreover, 84% of respondents explained ‘often’ or ‘very frequently’ referring patients with dissociative seizures to relevant websites e.g. [www.neurosymbols.org](http://www.neurosymbols.org), [www.nonepilepticattacks.info](http://www.nonepilepticattacks.info).

When asked to provide any additional thoughts about the CODES project, doctors indicated they were pleased that: the study generated data of relevance to psychological intervention for dissociative seizures; it has helped to raise understanding and awareness of dissociative seizures; the pathway has meant patients avoided existing waiting lists as well as providing much needed and quicker access to assessment or treatment for dissociative seizures; it facilitated multi-centered collaboration which was perceived as “a lasting legacy of the trial”; and also that it has raised questions as to how and by whom patients with dissociative seizures should be treated. Two doctors wished for additional clinical resources i.e. to meet the increased demand caused by the CODES trial, while another explained the problems encountered by patients having to travel long distances to receive care during the CODES study.

**Table 2**

Usual follow-up practice for patients with dissociative seizures (n.b. doctors could endorse multiple response options).

	Before	During	Since
No follow-up provided	5.8% (n = 4)	4.3% (n = 3)	3.1% (n = 2)
Only follow-up for additional neurological comorbidities	21.7% (n = 15)	20% (n = 14)	17.2% (n = 11)
Until patient has some confidence in and accepts diagnosis	30.4% (n = 21)	25.7% (n = 18)	28.1% (n = 18)
Until dissociative seizures are controlled	4.3% (n = 3)	10% (n = 7)	10.9% (n = 7)
Until AED is withdrawn	20.3% (n = 14)	20% (n = 14)	18.8% (n = 12)
Until dissociative seizures are controlled and AED is withdrawn	11.6% (n = 8)	10% (n = 7)	12.5% (n = 8)
Other	5.8% (n = 4)	10% (n = 7)	9.4% (n = 6)

AED = Anti-Epileptic Drug.

#### 4. Discussion

Although many neurologists fail to see the care of this patient group as their responsibility beyond diagnosis [2,10] and perceive such individuals as “challenging” and “frustrating” to care for [7], it was surprisingly easy to get a considerable number of neurologists throughout the UK to contribute to recruitment for a trial of a novel psychologically enhanced treatment pathway for dissociative seizures. The results here suggest that, in this group of neurologists, the negative attitudes toward individuals with the condition that emerges from previous interview and questionnaire studies do not apply [7]. The apparent resistance to involvement in the treatment of patients with dissociative seizures may, at least in part, be due to a lack of available treatment resources (including care pathways and information sheets) and lack of confidence in delivering or discussing the diagnosis and treatment options with patients, rather than a principled objection to treating such patients or to psychological therapies as such.

Fourteen doctors agreed that, during the trial, they were more likely to consider dissociative seizures as a potential diagnosis at an earlier stage of the usual investigation process. This suggests that the lack of access to treatment or awareness of the condition may actually be one of the reasons for the diagnostic delays which have previously been reported in patients with dissociative seizures [11,12].

Research has demonstrated that the reaction of patients with dissociative seizures to the diagnosis and suggestion of psychological treatment is strongly influenced by doctors' explanations of dissociative seizures [13]. While the doctors contributing to this study did not feel more confident in recommending psychological intervention to patients at the end of the trial, having an understanding of what the treatment entails may influence what is discussed during consultations and allow patients to have more of their questions answered and be given more information, thereby reducing patients' apprehensions about the next steps of care.

Over 90% of doctors who participated in this study agreed that they would like the care pathway to continue within their service, with at least one-third explaining that they had changed their practice towards patients with dissociative seizures following their participation in the

CODES trial, for instance by making more referrals to other professionals or directly to psychological intervention and having more structured and fruitful discussions with patients about their diagnosis. Most doctors found different elements of the CODES study useful, more specifically: the patient factsheet booklet (98%), diagnosis communication advice (93%), the CBT package (93%), neurological follow-up (84%), and psychiatric assessment (72%). The majority (83.7%) of respondents found it easy to recruit for the trial and felt that patient satisfaction for the psychiatric care and CBT treatment developed for the CODES study was ‘very good’. Neurologist perception of satisfaction is not the same as patient rated satisfaction. Nonetheless, this result is striking in the context of previous studies generally painting a negative picture of how hard neurologists find it to explain dissociative seizures to patients [7,14] and motivate them to engage in psychological treatment [6].

##### 4.1. Limitations

The response rate for the online survey was moderate at 51% with participants likely to have been biased towards neurologists with a keen interest in the condition or study. As participants' responses were anonymous we are unable to differentiate between subgroups of respondents; for example, many neurologists only referred a single patient into the CODES study so their responses were based on limited experience. Our results are based entirely on neurologists' self-report and may not reflect, for example, how well the explanation of the diagnosis was received by patients in practice. Other publications about the CODES trial (using quantitative and qualitative methods) will provide complimentary insights.

##### 4.2. Conclusions

There is growing interest in exploring the attitudes of healthcare professionals towards dissociative seizures. We are encouraged by the finding that we were able to recruit 43 neurologists in the UK who self-reported a good understanding of dissociative seizures, felt confident treating and recruiting individuals into a treatment trial for dissociative

**Table 3**

Opinions regarding CODES study components.

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Not Sure
Very good patient satisfaction for the psychiatric care	30.2% (n = 13)	39.5% (n = 17)	14% (n = 6)	4.7% (n = 2)	2.3% (n = 1)	9.3% (n = 4)
Very good patient satisfaction for CBT developed for CODES	27.9% (n = 12)	51.2% (n = 22)	9.3% (n = 4)	2.3% (n = 1)	0% (n = 0)	9.3% (n = 4)
Would like the pathway to continue	60.5% (n = 26)	30.2% (n = 13)	9.3% (n = 4)	0% (n = 0)	0% (n = 0)	–
Easy to recruit patients	39.5% (n = 17)	44.2% (n = 19)	11.6% (n = 5)	2.3% (n = 1)	2.3% (n = 1)	–
Easy to keep patients with dissociative seizures engaged in CODES	14% (n = 6)	48.8% (n = 21)	34.9% (n = 15)	2.3% (n = 1)	0% (n = 0)	–

CBT = Cognitive Behavioural Therapy.

**Table 4**  
Usefulness of elements of the CODES study.

	Extremely	Very	Moderately	Slightly	Not at all	Not aware
Diagnosis communication advice for neurologists	18.6% (n = 8)	53.5% (n = 23)	18.5% (n = 8)	2.3% (n = 1)	4.7% (n = 2)	2.3% (n = 1)
Patient fact sheet/booklet	48.8% (n = 21)	32.6% (n = 14)	14% (n = 6)	2.3% (n = 1)	0% (n = 0)	2.3% (n = 1)
Psychiatric assessment	34.9% (n = 15)	44.2% (n = 19)	16.3% (n = 7)	0% (n = 0)	0% (n = 10)	4.7% (n = 2)
Neurological follow-up	7% (n = 3)	46.5% (n = 20)	20.9% (n = 9)	9.3% (n = 4)	4.7% (n = 2)	11.6% (n = 5)
CBT for those who received it	34.9% (n = 15)	51.2% (n = 22)	4.7% (n = 2)	2.3% (n = 1)	0% (n = 0)	7% (n = 3)

CBT = Cognitive Behavioural Therapy.

seizures and who (for the most part) provided follow-up. The participating doctors reported diagnosing a median of three patients a month with dissociative seizures; however, before and after the trial, only about one-half could make direct referrals to psychological intervention specific for dissociative seizures. Our results demonstrate that neurologists find additional resources such as a patient factsheet booklet and diagnosis communication advice (as well as a clear management pathway) useful when providing care for individuals with dissociative seizures. The vast majority of neurologists who responded to our online survey reported wanting the treatment pathway developed for the CODES trial to continue within their service, demonstrating their interest in taking on an active role in the management of dissociative seizures. While the results suggest that progress is being made, the fact that many neurologists participating in the CODES study lost the ability to offer patients psychotherapy again after the end of the study recruitment period means that problems with lack of access to psychological treatment for dissociative seizures persist.

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### Conflict of interests

Prof. Carson reports being a paid editor of the Journal of Neurology, Neurosurgery and Psychiatry, and is the director of a research programme on functional neurological disorders; he gives independent testimony in Court on a range of neuropsychiatric topics (50% pursuer, 50% defender). Prof. Stone reports independent expert testimony work for personal injury and medical negligence claims, royalties from UpToDate for articles on functional neurological disorder and runs a free non-profit self-help website, [www.neurosymptoms.org](http://www.neurosymptoms.org). The authors have no other conflict of interests to declare.

### Ethical publication statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines. Ethical approval was granted by the London-Camberwell St Giles NRES Committee (reference number 13/LO/1595).

### Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.seizure.2019.05.020>.

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