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A multicentre evaluation of a brief manualised psychoeducation intervention for Psychogenic Non-Epileptic Seizures delivered by health professionals with limited experience in psychological treatment

Psychogenic Non-Epileptic Seizures (PNES) are one of the most common differential diagnoses of epilepsy. The incidence of PNES has been reported as 4.9 per 100,000 [1], however, this may well be an underestimate, as this figure only includes cases referred and presenting to a specialist clinic [2]. PNES are often chronic and the prevalence of the disorder may be as high as 33/100.000 [3]. Despite this high prevalence, there are no evidence-based standard care pathways for managing this condition [4] [5]. A survey distributed to 130 practitioners in the UK who work with this patient population, showed that 93% of health professionals believe these patients should be offered psychological treatment as the treatment of choice [4]. However, only 35% of practitioners were able to refer all of their patients for this treatment and 15% were unable to provide this treatment option to any of their patients.

Recent, small scale randomised controlled trials have demonstrated the benefits of psychological treatment for PNES, including reduction in seizure frequency as well as improvement in psychosocial functioning [6 7], and an uncontrolled long-term study suggested that the positive effects of psychotherapy are likely to persist [8]. However, it has been shown that patients with PNES preferentially endorse physical factors as being responsible for their seizures and are resistant to the sort of psychological explanations of their difficulties which may be provided by neurologists [9]. As a result, many patients find it hard to accept that psychological treatment would be beneficial to treating their condition [10], and nearly half of all patients diagnosed by neurologists with functional symptoms struggle, or entirely fail, to engage in a treatment program after they have been referred for psychotherapy [11].

We previously developed a communication strategy which provided guidelines for neurologists to deliver the diagnosis of PNES and which included an information booklet intended to back up their verbal explanation in writing. An evaluation showed that 86% of patients acknowledged that psychological symptoms contributed towards their symptoms when this protocol had been followed [12]. The explanation of the condition based on this strategy was also associated with a decrease in seizure frequency, with PNES stopping altogether in one in six patients. However, in the absence of further intervention, impairment in quality of life measures persisted, indicating a need for a more active or persistent treatment approach not limited to the explanation of the diagnosis alone [12].

The communication strategy was conceived as Step 1 of a stepped care model of care for patients with PNES. Step 2 of this stepped care model involves a brief manualised one-to-one psychoeducation intervention designed to help patients better understand their diagnosis and to improve their ability to self-manage their symptoms. This intervention was intended to be delivered by clinicians with very limited psychological treatment experience. Following this step, individuals needing more extensive psychological treatment can go on to receive individualised psychotherapy (Step 3).

The psychoeducation program designed for Step 2 of this approach was intended to be sufficient as a standalone treatment for some individuals. At the same time, the program was conceived to help other patients to engage in further psychotherapy and to understand the rationale for this treatment modality.

We previously showed that three healthcare professionals with minimal experience in psychological treatment were able to deliver this psychoeducation intervention following a brief one-day training [13]. Thirteen out of twenty patients followed in our pilot study completed the intervention, and the programme seemed to have a greater effect in terms of PNES reduction than patients receiving the communication strategy alone [12]: 31% of participants became seizure free after receiving the

psychoeducation intervention, and a further 25% reported a significant reduction in their seizure frequency [13].

Given the positive outcome of this pilot project, further evaluation of the intervention was justified. The present multicentre service evaluation of our psychoeducation intervention was conducted to add to our understanding of the impact of this intervention on patients' acceptance of the diagnosis of PNES, the frequency of their seizures and their quality of life. We also wanted to assess whether the intervention can be rolled out successfully to be delivered by a more diverse range of clinicians and in a wider range of treatment settings.

Method

Patients

Adult patients were recruited consecutively from December 2013 to February 2016 in four hospital trusts in the UK; Sheffield Teaching Hospitals (STH), Nottingham University Hospital, Huddersfield and Calderdale NHS Foundation trust, and Derby Hospitals Foundation Trust. In total, nine health professionals were involved in delivering the intervention. Four were based in Sheffield, two in Nottingham, two in Huddersfield and one in Derby. Three of the ten practitioners involved were assistant psychologists (which meant that they had an undergraduate degree in Psychology and some basic understanding of psychotherapy), one was an occupational therapist, and the remaining six were specialist epilepsy nurses. Only one of the practitioners was male.

Although not all professionals were based in neurology services, all patients were referred for psychoeducation after the diagnosis of PNES had been made and communicated by neurologists. Referral procedures varied. The majority of the patients involved were treated at STH. This hospital has a specialist neurology psychotherapy service which is not widely available in other parts of the UK. As a matter of routine, most patients diagnosed with PNES at STH would be offered a stepped care approach. Following the explanation of the diagnosis by the neurologist, they would be

provided with access to psychoeducation if seizures persisted. Patients still symptomatic after psychoeducation would be referred for psychotherapy. However, exceptions from this routine care pathway are possible. Patients at STH are triaged on the basis of the referral letter from the neurologist to the psychotherapy service, and self-report data provided in their response to a postal screening questionnaire, the Clinical Outcome Routine Evaluation (CORE) measure. Patients assessed as having serious, complex mental health problems or at risk of suicide were not selected for psychoeducation, but were referred straight to psychotherapy.

In Nottingham, all patients referred with PNES were assessed by a clinical psychologist. Following this assessment, patients were selected for psychoeducation if they were considered to be low risk (based on responses to the CORE and to clinical interview questions) and if they were thought to be engaged and motivated to complete the program. The psychologist tried to include patients whom she felt were not resistant to the psychological explanation of seizures. In Derby the patients were seen by an Occupational Therapist who only accepts referrals for individuals with comorbid chronic fatigue and PNES. Following the four sessions of psychoeducation, three of the four centres were able to offer longer-term psychotherapy for those patients who required additional input.

Not all patients described here had video-EEG proven diagnoses of PNES, but this diagnosis was sufficiently likely for the referring neurologists to consider psychological treatment appropriate. Patients thought to have comorbid diagnoses of PNES and ES were not excluded from this service evaluation, however only two patient in this sample had both diagnoses.

Eligible patients were contacted by phone by the health professional who would be delivering the intervention. They were informed that this program would allow them to discuss their diagnosis and would teach them some simple strategies to manage their seizures. Patients were informed that their involvement was voluntary. Patients recruited at STH were told that they could wait to be offered individualised psychotherapy even if they did not want to be involved in the

psychoeducation program. They were told that their place on the waiting list for psychotherapy would not be affected by their decision about accessing psychoeducation.

Psychoeducation intervention

The psychoeducation intervention is fully manualised and consists of four one-hour sessions which are designed to be delivered by individuals with limited experience in psychological intervention. The programme is intended to be delivered within days or a small number of weeks after the communication of the diagnosis. It aims to enable some patients to learn how to control their seizures, and to provide those whose PNES fail to stop with a better understanding of why further treatment with individualised psychotherapy might be useful. By providing an accessible explanation of PNES, and by offering patients space and time to discuss their feelings around and understanding of the diagnosis, the protocol aims to address some of the most common experiences of individuals following diagnosis, including confusion and a sense of distrust [14 15].

The psychoeducation intervention also aims to identify patterns of anxiety and avoidance which might not be recognised or acknowledged by the patient but which might contribute to or perpetuate their symptoms [16] [17]. Further information about the specific sessions of the intervention is provided in Table 1.

Self-report measures

Patients who opted for psychoeducation were sent a questionnaire with a range of self-report measures to complete and bring to the first session as a baseline measure of seizure frequency and functioning (described in detail below). At the end of the fourth and final session patients were asked to complete the same questionnaire. They were also asked some additional questions about how useful and comprehensible they found the psychoeducation program.

Seizure Frequency

Patients were asked to report their PNES frequency over the month preceding the intervention on the basis of diaries if available, or to estimate their PNES frequency in the past month if not.

Following intervention patients were asked to document the number of seizures that they had experienced in the past month. Individuals who reported no seizures at this time point were considered to be seizure free at the end of the study. For the purpose of analysis, each patient's seizure frequency was calculated as PNES per month.

Work and Social Adjustment Scale (WSAS)

The work and social adjustment scale is a five item measure which is used to determine the extent to which an individual believes that their work and social functioning is impaired. Individuals rate the extent to which their home management, daily living activities, leisure activities and family relationships are impacted on a scale of 1 (Not at all impaired) to 8 (Very impaired) [18]. This scale has been used in several previous studies with this patient group and proven a useful and sensitive measure of treatment-related change [19].

Clinical Outcomes in Routine Evaluation outcome measure (CORE-OM)

This 10-item self-report measure is designed to be used before and after therapy. It covers domains of subjective wellbeing, life functioning, problems and symptoms. There is a high correlation between this measure and other measures of wellbeing, including Becks Depression Inventory [20] and the Symptom Checklist-90 Revised [21]. The CORE has been used across several clinical settings, and has been found to be sensitive to change [21]. It has been effectively used to measure change in individuals following a group psychoeducation program for anxiety [22]. This measure has also been used to demonstrate psychotherapy associated improvements in the PNES patient group [23].

Brief Illness Perception Questionnaire (IPQ)

The BIPQ consists of five subscales which are thought to underlie the cognitive representations of illness. It assesses how people perceive their illness in relation to its identity, causes, consequences, time-line and cure control [24]. The brief version of this scale used in this study consists of eight items which require ratings on a ten-point Likert scale. It has been shown to be reliable and valid for use in a number of settings with chronic illness [24]. A lower BIPQ score shows that an individual has a more positive perception of their illness.

NewQOL -6D

The NewQOL was recently developed to be the first epilepsy-specific QALY measure (Quality Adjusted Life Year) [25]. It is a six-item-measure in which individuals choose one of four responses that best describes how they feel in relation to worry, depression, memory, concentration, control and stigma. Patients' responses can be converted to utility scores which can then be used to generate QALYS. QALYS are used as a measure to help with resource allocation in health services. For the purpose of this study the NEWQOL-6D provided a measure of health related quality of life.

ED-QOL

The ED-QOL is a standardised instrument which has previously been used to measure health outcomes in a range of patient populations including rheumatoid arthritis [26] and multiple musculoskeletal disorders [27]. It is a 5 item measure in which individuals describe their health state from 1 (no problems) to 3 (extreme problems) in regards to mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. This measure assesses quality of life and is sensitive to change across these domains.

Symptom Attribution

Patients were asked to complete a simple symptom attribution questionnaire which required them to rate the extent to which they thought physical or psychological factors contributed to their symptoms. This scale has previously been used with patient populations, including those with chronic fatigue, PNES and epilepsy [9 28].

Intervention feedback

Patients were asked about the usefulness and relevance of the psychoeducation intervention in relation to understanding and being able to control their non-epileptic seizures better. The questions were asked on a Likert scale, with 1 meaning “not at all” and 10 meaning “totally” or “extremely”.

Statistical Analysis

Tests of normality showed that the data was not normally distributed. Therefore non-parametric tests for repeated measures were used to analyse this data. Wilcoxon signed ranks tests were conducted to compare data from individuals before and after they received the psychoeducation intervention. For the purposes of this study, significance was only considered for two-sided p-values off less than <0.05. Table 2 presents the median and interquartile range for the pre- and post-intervention data as measured by the self-report questionnaires.

Results

Participants

Forty suitable patients were identified from across the four sites between January 2014 and February 2016. Figure 1 presents the pathways of the forty patients that were approached and shows the proportion of these that were non-contactable, did not attend psychoeducation, or did not complete the program.

Out of the 36 that agreed to take up the offer of a psychoeducation programme, 7 (19%) failed to come for their first appointment and were discharged from the programme. However, 4 of the 29 patients (14%) who enrolled failed to complete the following three psychoeducation sessions. The remaining 25 participants are included in this evaluation and 19 (76%) of these patients completed and returned the post-treatment questionnaire. For further information on participants, see Table 2.

All self-report scores improved with treatment although only the score changes on the measures of distress (CORE) and illness perception (IPQ) reached significance (Please see Table 3). The baseline results for the CORE-10 indicate that prior to the intervention, psychological distress (mean = 2.3), was significantly higher than post intervention (mean = 1.8).

In total, 19 patients provided post-treatment feedback, but one of these lacked seizure information. Therefore, at the end of the program, 6 out of 18 patients (33%) that provided post-intervention seizure data had been seizure free for the past month. An additional 6 out of 18 patients (33%) had achieved seizure frequency reduction. Therefore, upon completion of the intervention, 12 out of 18 patients (67%) were either seizure free or experienced fewer seizures compared to the start of the intervention. The reduction in the frequency of PNES (from a median of 8 per month to a median of 3 per month) was considerable but did not reach statistical significance because of the wide range of reported PNES frequencies (2-168 per month pre-treatment and 0-70 per month post-treatment). Table 4 shows how patients rated their satisfaction with the intervention (with scores ranging from 0="not at all" to 10="totally" / "extremely").

Discussion

This evaluation provides further evidence that it is possible for health professionals with minimal experience in psychological treatment to provide an effective brief psychoeducation program for individuals with PNES. While short-term seizure cessation cannot be the only treatment goal in this patient group [35], it is clearly relevant and was achieved in one third of patients.

Engagement with treatment

Our findings showed that individuals with PNES can be reluctant to engage with psychological treatment initially and, 7 out of 36 (19%) individuals did not turn up to their first appointment after agreeing to attend via telephone. Once individuals did attend for an initial appointment, 4 out of 29 (14%) individuals dropped out of the intervention. Out of the remaining 25 individuals that completed the intervention, 6 (24%) failed to subsequently complete the post-treatment questionnaires.

This high rate of non-attendance for initial appointments is in line with other research looking at how patients with PNES and other functional symptoms engage in psychological treatment [11]. However, whereas the previous research revealed a completion rate of only 66% once individuals had started to attend for therapy, our study had an 86% completion rate, which was similar to the 85% completion rate observed during the initial pilot study of the programme [13]. The difference in completion rate may be explained by the brevity or structure of the psychoeducation intervention. However, at least in part, the difference may also be related to case selection. Especially in Sheffield, where most patients were recruited for this service evaluation, many patients were referred directly to the psychotherapy service because they were considered to be at high risk of suicidality (as measured by the CORE) or because they had particularly complex comorbid problems. These patients may have been more likely to drop out of psychotherapy or not to attend in the first place. Having said that, the baseline variables show that even the participants deemed suitable for this psychoeducation program showed high levels of distress and psychopathology at baseline.

Some patients who were told about the diagnosis of PNES may have decided not to take up the offer of psychoeducation because their seizures had stopped. However, others may have failed to understand the rationale for the intervention. Further improvements of the initial communication practice, or more support after the initial communication could therefore be helpful. One previous

study has demonstrated that follow-up telephone calls by a member of the neurological treatment team can increase engagement in psychological treatment [36]

Seizure outcomes

Following completion of the program, seizure frequency of the overall sample approached significance but did not significantly change between pre and post time points. However, 6 out of the 18 (33%) patients that provided post-intervention seizure frequency information had experienced complete seizure cessation for the previous month. This is comparable to the feasibility study by Mayor et al. which documented total cessation in 31% of patients [13]. This suggests that the psychoeducation intervention is more effective in reducing seizure frequency than communication of the diagnosis on its own, which was previously only associated with the (short term) cessation of PNES in 16% of patients when the same communication strategy was used as in the current service evaluation [12]. Chen et al. [31] previously evaluated a psychoeducation program for PNES which also showed that seizure frequency did not decrease in line with the intervention.

Understanding of the diagnosis

Given the educational focus of the intervention, it was encouraging to note the significant improvements in the understanding of the disorder as demonstrated by change in the IPQ-R. Following the intervention 42% of individuals considered their seizures to have an entirely psychological basis, in comparison to 26% of individuals who believed this prior to undergoing treatment. Following intervention, the remaining 58% of individuals endorsed psychological factors as contributing somewhat to their symptoms. Upon completion of the programme, none of the individuals believed that their symptoms were due to exclusively physical factors, in comparison to 13% of individuals who believed that this was the case before starting their treatment. Mayor et al. previously showed that patients' symptom attributions did not vary much before and after receiving the diagnosis of PNES [12]. Psychoeducation may be an effective follow up to diagnosis, in helping

individuals to fully understand the psychological explanation of their symptoms and providing a rationale for psychotherapy for those individuals requiring more intensive psychological treatment.

Well-being outcomes

Prior to the psychoeducation intervention, patients showed high levels of psychological distress and impaired functioning, as well as a health-related quality of life that was comparable to medical conditions. The baseline results for the WSAS (mean = 24.2), indicated a more severe impairment of functioning when compared to people with mild-to-moderate depression, anxiety and stress (mean=17) [32]. The health-related quality of life result (EQ-5D) baseline (mean = 0.7) is comparable to those with diabetes (mean = 0.7) and just below epilepsy (mean =0.8) and asthma (mean = 0.8) [34].

Psychoeducation has previously been found to be effective in helping individuals with other disorders, including anxiety and depression [30]. Additionally Chen et al. [31] evaluated a psychoeducation program for PNES and showed that participants receiving the intervention improved on a measure of work and social functioning, and reduced their utilisation of emergency healthcare services.

Our study similarly showed that significant improvements on outcomes other than seizure frequency can occur following psychoeducation. Individuals reported significantly less psychological distress, as measured by the CORE measure.

There was no significant improvement in the HRQoL measures used in this study. Likewise, improvements in terms of work and social adjustment (WSAS) failed to reach significance. Improvements in HRQoL measures and the WSAS have previously been observed with brief psychoeducation [23, 31] and with more intensive psychotherapy programmes for PNES [19] but not with the explanation of the diagnosis alone [12]. This suggests that more extensive psychological

input than the explanation of the diagnosis alone or a short course of psychoeducation may be necessary to improve overall functioning and quality of life in patients with PNES.

Acceptability of the intervention

All individuals except one reported that the program had helped them to understand their attacks better and that it had been relevant to their difficulties. All patients except two acknowledged that the intervention had helped them to control their attacks better. All patients except one reported that the program was clear and comprehensible, and all said that they would recommend the program to others, with the majority rating 'yes absolutely' in agreement with this question.

Further intervention

Of the patients in Sheffield who completed the psycho-education program, 15 out of 19 (79%) went on to receive further psychotherapy and out of the remaining four patients, three (16%) felt that psychoeducation alone had been sufficient in helping them cope with their seizures. Similarly the patient in Derby felt that the psychoeducation program alone was sufficient.

Limitations

This evaluation took place in a range of clinical settings and although this increases the likelihood that the findings will be applicable to practice in real life, it also has some limitations. The way in which different services are organised vary considerably across the country and even within the four centres included in this study practice will differ. Whilst psychoeducation seems to be effective following diagnosis by a knowledgeable neurologist and preceding potential psychotherapy in a specialist service, it is unknown how useful this program would be if it was offered in a different setting.

Additionally, most of the patients in this study were triaged so that only low risk individuals were offered psycho education. As such it is not known how more complex or more distressed PNES patients would respond to the intervention.

This study did not include a control group; therefore it is not possible to evaluate the effectiveness of psycho-education in comparison to any other treatment option or to no treatment at all. Previous research has found that some individuals become better after receiving the diagnosis of this disorder alone [12], therefore it is not possible to conclude that any of the positive outcomes were a result of the psycho-education program alone.

The number of patients recruited was small, and therefore the study is underpowered. This may have contributed to the inability to detect statistically significant effects, especially as the magnitude of the difference between pre- and post-intervention scores was medium to large for all measures. Additionally a follow-up period was not included in this study. Further, larger scale studies evaluating the effectiveness of this treatment approach and longer lasting outcomes could usefully contribute to the development of a stepped care model to treat PNES. Future evaluations would also do well to investigate the factors which have contributed to the drop-out rate within the programme and how to continue increasing engagement with psychoeducation.

Conclusion

Despite these limitations this study provides further evidence suggesting that brief psychoeducation is an effective intervention for individuals with PNES, and can have a positive impact on both seizure control and on additional well-being outcomes. It provides a more comprehensive explanation of PNES than the communication protocol alone, which may allow individuals to have a better and more adaptive perception of their symptoms. Individuals appear more willing to endorse psychological factors as contributing to their difficulties which might promote engagement with further psychological treatment

However, it seems that psychoeducation as a stand-alone intervention may not be sufficient for most patients, and many individuals with PNES are likely to benefit from further psychological input. In particular, psychoeducation does not seem to have a significant impact on levels of functioning which have previously been shown to be improvable with individualised psychotherapy [23], and further intervention may target aspects of work and social adjustment more effectively.

This evaluation provides evidence that psychoeducation could usefully be included as part of a stepped care model for treating PNES. For some individuals it may provide a sufficient level of intervention, over and above that of communication of the diagnosis alone, whilst for others, additional psychotherapeutic work will be required.

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