

A Multidisciplinary Approach to Conversion Disorder with Nonepileptic Seizures: A Case Study

A Tickle, H Crockford

Citation

A Tickle, H Crockford. *A Multidisciplinary Approach to Conversion Disorder with Nonepileptic Seizures: A Case Study*. The Internet Journal of Mental Health. 2009 Volume 7 Number 1.

Abstract

There are several treatment options for conversion disorder, but none have emerged as a treatment of choice. This case report describes one woman's experiences of conversion disorder and the multidisciplinary and multi-agency care plan developed to meet her needs. It offers reflections from the perspective of staff and the patient herself about which aspects of the treatment were most effective. The study aims to give insight into the benefits and the gaps of the programme. This is a descriptive case study arising from collaboration between client and professionals throughout the period of the care plan. It concludes that the multidisciplinary and multi-agency approach has much to offer in the treatment of conversion disorder.

INTRODUCTION

CONVERSION DISORDER

Conversion disorder is part of the group of somatoform disorders⁽¹⁾, with the DSM-IV criteria as follows⁽²⁾:

- a) One or more symptoms or deficits affecting voluntary motor or sensory function that suggest a neurological or other general medical condition.
- b) Psychological factors are judged to be associated with the symptom or deficit because the initiation or exacerbation of the symptom or deficit is preceded by conflicts or other stressors.
- c) The symptom or deficit is not intentionally produced or feigned (as in Factitious Disorder or Malingering).
- d) The symptoms or deficit cannot, after appropriate investigation, be fully explained by a general medical condition, or by the direct effects of a substance, or as culturally sanctioned behaviour or experiences.
- e) The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or warrants medical evaluation.
- f) The symptom or deficit is not limited to pain or sexual dysfunction, does not occur exclusively during the course of Somatization Disorder, and is not better accounted for by another mental disorder.

Conversion has been attributed to many different mechanisms⁽³⁾, with some of the proposed etiologies including neuroanatomical, psychodynamic with trauma and dissociation, cognitive-behavioural, volitional feigning with conscious or unconscious awareness, communication difficulties and disturbances in the family system⁽⁴⁾. Symptoms include amnesia⁽⁵⁾, seizures⁽³⁾ and weakness or even paralysis⁽⁶⁾. Some conversion symptoms last hours to days, while others linger or even result in permanent complications, such as disuse contractures of a paralysed limb⁽⁵⁾.

Psychogenic nonepileptic seizures (PNES) are one of the common symptoms of conversion disorder⁽³⁾. They occur in 15% of all conversion patients⁽⁶⁾ and are sometimes referred to as 'dissociative seizures'⁽⁷⁾ or 'pseudoseizures'⁽⁸⁾. Clinicians readily admit feeling ill equipped to care for patients with PNES⁽⁴⁾, which may contribute to explaining the relative paucity of theoretical papers and treatment trials. However, there has been some recent interest in the treatment of both PNES⁽⁴⁾ and conversion disorder more generally⁽³⁾. Both are relevant to the current case study.

There is some evidence in the literature regarding the possibility that patients with conversion disorder may be viewed as difficult to help and may be subject to pejorative attitudes by clinicians or those around them. For example, neurologists have been found to perceive patients with predominantly unexplained symptoms to be more difficult to help than those whose symptoms were explained by

neurological disease⁽⁹⁾. Such perceptions are important to consider because of the possibility that they may impact on the interactions between clinicians and patients and ultimately on treatment effectiveness.

Nettleton⁽¹⁰⁾ highlights the context of a society that does not readily grant permission to be ill in the absence of disease. In the United States and United Kingdom, pejorative views may be linked to newspapers' disparaging use of the term 'psychosomatic' to mean an illness that is not important or is imaginary, malingered or representative of a character flaw⁽¹¹⁾. Stone et al.⁽¹¹⁾ raise the potentially serious problem of acceptability for those with psychosomatic difficulties. This is reiterated by a study that found negative attitudes towards patients with conversion symptoms on neurology wards were common, albeit not held by the majority of nurses⁽¹²⁾. Examples included 46% of the 68 nurses who participated viewing patients as 'manipulative' and 16% disagreeing that conversion symptoms were 'real'⁽¹²⁾.

Owens and Dein⁽³⁾ (p. 155) emphasise the importance of nursing and medical staff avoiding the labelling of individuals diagnosed with conversion disorder 'as being manipulative, dependent or as exaggerating their difficulties', in order to establish a therapeutic alliance and enable recovery with dignity. This could be seen as a philosophy that can underpin any approach to the treatment of somebody diagnosed with conversion disorder, regardless of the specific treatment utilised. It is also an approach supported by findings relating to the experience of patients with medically unexplained symptoms, which suggest the importance of friends, family and particularly health professionals acknowledging symptoms as 'genuine'⁽¹⁰⁾. This is reiterated by the finding that perceptions of doubt from medical professionals, society and even friends and family were reported to contribute to feelings of isolation and distress among those with nonepileptic seizures⁽¹³⁾. In addition to evidence from those experiencing NES, recognition of symptoms as 'genuine' is also in line with the general acceptance that direct confrontation is an ineffective approach and that 'more supportive, insight-oriented, cognitive, and behavioural techniques' are recommended to focus on understanding symptoms within a biopsychosocial framework⁽¹⁴⁾.

There are several treatment options for conversion symptoms. There is some evidence that both suggestive and behavioural therapeutic techniques and eclectic treatment programmes are effective in the treatment of conversion

symptoms⁽¹⁵⁾. It must be acknowledged that many patients fail to follow through with, or benefit from, psychological or psychiatric intervention⁽⁶⁾. However, although no specific intervention has emerged as the treatment of choice⁽¹⁶⁾, an evidence base is emerging in support of the effectiveness of psychotherapy and variants of cognitive-behavioural therapy are the mainstay of treatment⁽¹⁷⁾. Controlled research into the treatment of conversion symptoms is scarce and can often be criticized on methodological grounds⁽¹⁸⁾, although this is widely acknowledged and randomised controlled trials are now taking place⁽¹⁹⁾.

Howlett and Reuber⁽²⁰⁾ describe an approach grounded in psychodynamic interpersonal therapy but augmented with elements of cognitive-behavioural therapy, somatic trauma therapy and the involvement of caregivers and family members. They hypothesise that the mechanisms for change are the identification and alternation of problematic interpersonal patterns and the processing of repressed or unrecognised emotions. A pilot study⁽²¹⁾ found this approach to be associated with significant improvements in all outcome measures used, which included measures of subjective well-being, symptoms, risk, physical functioning, role limitations due to emotional problems and mental health. Such improvements appeared to be maintained 6 months after the cessation of therapy⁽²¹⁾.

Several studies have supported the efficacy of cognitive-behavioural therapy for PNES. A pilot study of the use of 12 sessions of CBT for 20 patients with PNES suggested that those who completed the programme demonstrated a significant reduction in seizure frequency and an improvement in self-rated psychosocial functioning both post-treatment and at six-month follow-up⁽⁷⁾. This finding was further supported by a study of a 12 week manualised CBT for PNES study, in which 11 of the 17 individuals who completed reported no seizures by their final session, as well as improvement on scales of depression, anxiety, somatic symptoms, quality of life and psychosocial functioning⁽²²⁾. A later pilot randomised controlled trial⁽¹⁹⁾ compared CBT with standard medical care and found CBT to be superior in leading to seizure reduction at treatment end. In addition, those in the CBT group tended to be more likely to have been free of seizures for three months at six-month follow-up.

In addition to psychotherapy, pharmacological treatments might be used. A recent double-blind, randomised, placebo-controlled trial found that PNES were reduced in patients

treated with a serotonin selective reuptake inhibitor. In contrast, those treated with placebo experienced a slight increase in PNES⁽²³⁾. Pharmacological treatments might be used in isolation, or be augmented with psychological treatment, even in the absence of axis I disorders such as depression⁽¹⁷⁾. However, there is little strong evidence available in relation to pharmacological treatments and further research is necessary.

Aside from a small number of articles^(14, 20, 24, 25), there is limited literature that describes the treatment of conversion symptoms. The available literature focuses on different aspects or types of treatment, in both inpatient⁽¹⁵⁾ and outpatient settings⁽²⁵⁾. LaFrance and Barry⁽⁴⁾ (p.367) assert that 'a multidisciplinary approach may provide distinct advantages for treatment' of PNES. This is supported by a review of nondrug treatments for PNES, which concluded that prognosis is good when management takes place in a specialist unit with a multidisciplinary approach and team familiar with the patient group⁽¹⁸⁾. However, multidisciplinary or multispeciality⁽²⁶⁾ approaches may comprise a range of treatments. There appears to be a lack of literature that describes a multi-disciplinary approach to outpatient treatment of conversion. There is also an absence in the literature of patients' perspectives about their experiences of treatment. It is this scarcity that generated the initial motivation to report this case study. Quotations from the patient are included throughout the present case study to explicitly incorporate her perspective. She worked with the first author to record her views in writing for the purposes of the case study and gave written authorisation for these quotes to be included.

The complex needs of an individual with conversion disorder can require a package of care that is multi-agency as well as multi-disciplinary. The descriptive nature of the current study aims to give a more accurate sense of the clinical reality of working with such a case.

CASE REPORT

Our patient (lets call her Lisa) was in her thirties when she presented to an Acute Day Treatment Unit. She had a history of treatment for depression and at the time of referral was receiving treatment by anti-depressants for post-natal depression. She described significant 'swings' to low mood, which occurred without warning. Lisa presented with a range of medically unexplained symptoms. She had begun to have seizures during the fifth month of her third pregnancy. These continued after the birth, with one resulting in an

inpatient admission to a neurological ward, seven months after the seizures began. Lisa was never diagnosed with epilepsy, which was eliminated as a cause of the seizures during the admission to the neurological ward.

At the time of referral to the Acute Day Treatment Unit, she was still experiencing seizures frequently – up to three times a day. She recognised that tiredness, stress, over-exertion and anger appeared to trigger seizures. Monitoring indicated that seizures lasted between four and seven minutes. It appeared that Lisa would experience a feeling of being 'vacant' as the seizure began and either fall to the floor or be put on the floor in a safe position by her partner. She was on occasion incontinent of urine during a seizure, but this was not the case during the majority. Lisa always felt tired and often slept after the seizures.

Lisa met the aforementioned DSM-IV criteria⁽²⁾ and was diagnosed with Conversion Disorder by the Psychiatrist during their first appointment, just over six months after the seizures began. Although several studies have shown that patients do better if PNES are recognised early⁽¹⁷⁾, more recent reviews of the evidence suggest that delay to diagnosis is not a predictive factor for outcome of PNES^(27, 28). Rather than diagnosis itself, there is some evidence that it is the patient's reaction to the diagnosis that has an impact on outcome and that an angry reaction is particularly associated with poor prognosis⁽²⁹⁾. It is impossible to say whether the timing of Lisa's diagnosis influenced the outcome of treatment. However, the elimination of epilepsy at an early stage did enable treatment to be appropriately tailored to address her needs. Lisa was able to talk about the diagnosis with professionals and appeared to accept it and want to work within a framework of understanding that viewed her seizures as psychogenic in origin.

Lisa reported amnesia for a thirteen-year period preceding the seizure that led to the inpatient admission. She also had a left-sided hemiparesis. While there is an assertion in the literature of predominant left-oriented manifestation of symptoms for most somatoform disorders⁽⁶⁾, alternative evidence suggests this perceived asymmetry results from a publication bias⁽³⁰⁾. Lisa was unable to use her left-hand, which appeared to be paralysed, although there was no evidence of muscular atrophy. On admission, Lisa was using a wheelchair. However, with encouragement from her Psychiatrist, she was able to leave the wheelchair and walk with the aid of a stick from their first appointment. She did not return to her wheelchair thereafter.

PRECIPITATING FACTORS

In July 2004, Lisa fled domestic violence with her two-year-old son. She reported that she left the home after her partner held a knife to her throat. She found it hard to give up her previous lifestyle, including two jobs as a support worker. Lisa began a new, loving relationship and became pregnant. She recalled this as a time that she felt very happy. In 2005, while Lisa was pregnant, her partner was arrested for the attempted murder of his ex-wife. While still pregnant, Lisa had her first seizure, resulting in amnesia for a three year period and left-side weakness. Following the birth of her daughter, Lisa became depressed, had poor mobility and frequent seizures. In December 2005, she experienced her most severe seizure, leading to the admission to a neurological ward. Following discharge, she was referred to the mental health Acute Day Treatment Unit. During this time, Lisa acknowledges that she let her partner “do everything” for her. He left her in April 2006 following a gradual breakdown in the relationship attributed to the pressure of his new role as a carer.

Lisa’s discussion of her relationship with her partner can be linked to evidence which suggests that many patients with conversion disorder derive primary or secondary gain⁽⁶⁾. For example, the conversion symptom may provide primary gain in avoiding immediate distress, and secondary gain in creating the ‘patient role’ from which the patient may derive subsequent benefits⁽³⁾. Although Lisa found it difficult to accept this notion when we reviewed the literature, she recognised that she had unconsciously taken on a strong ‘patient’ role. There is some evidence that such gain may operate as a perpetuating factor for a small number of individuals with NES and other functional neurological symptoms. Examples of secondary gain include an avoidance of responsibility and positive benefits of the role, such as eliciting a caring response from others⁽³¹⁾. Reuber et al found the gain of an ‘illness identity’ to be a perpetuating factor in just over 10% of participants in their study⁽³²⁾. This is a relatively small percentage and thus it is important to emphasise that this may not be a factor for many individuals experiencing PNES. However, it did appear to be relevant to Lisa. Approaching the topic of secondary gain where it is suspected to be relevant must be done sensitively in order to protect the therapeutic relationship. In this situation, discussing some of the available literature proved a useful technique for introducing the notion of secondary gain as a possibility for people who experience PNES in a non-threatening and non-blaming manner.

In many cases, the mechanism underlying the conversion symptoms is never identified, or is speculative⁽⁶⁾. It can be helpful to conceptualise two different levels with regard to the etiological significance of various factors: triggers for individual attacks and also the factors that may predispose, precipitate or maintain the disorder⁽³³⁾. A model of PNES should attempt to account for both. There is no widely agreed model as yet⁽³⁴⁾, although understanding is developing. For example, Baslet⁽³⁵⁾ proposes a conceptual framework that proposes individuals with PNES have a vulnerable cognitive-emotional processing system that can predispose individuals to PNES.

In relation to individual attacks, there is evidence that seizures may occur as a dissociative response to heightened arousal, even in the absence of raised general levels of anxiety. This might be thought of as “panic attack without the panic”^(31, 33). Many patients do not clearly identify stress as a trigger for individual attacks⁽³⁴⁾, but Lisa recognised the role of stress throughout. The mechanism of the seizures was thought largely to be dissociation that served to protect her from unpleasant or frightening emotional arousal, as described by Mellers⁽³⁴⁾. It was hypothesised that Lisa developed an adaptive ability to “switch off” during early experiences of abuse and that her seizures represented a re-emergence of this response when she experienced stressful situations⁽³⁴⁾.

Lisa’s seizure diary indicated several examples of seizures happening during a stressful situation, such as a ‘heated debate’ with her partner. However, there were other situations in which the seizures occurred without an apparent trigger other than tiredness. Tiredness could be viewed as a particular form of stress. Alternatively, it could be hypothesised that when Lisa was tired, she was more likely to experience fleeting stressful or unpleasant thoughts that she was barely aware of and had little to do with her immediate circumstances⁽³⁴⁾, but which raised her level of psychophysiological arousal to the extent that a dissociative seizure was triggered⁽³³⁾.

Lisa’s history included a high occurrence of factors associated with conversion symptoms. Through a combination of psycho-education about conversion disorder and a cognitive-behavioural formulation, we identified a number of possible contributory factors in Lisa’s case, outlined below.

A COGNITIVE-BEHAVIOURAL FORMULATION

EARLY EXPERIENCE

- Childhood dominated by alleged criticism from other family members, particularly relating to size and intelligence.
- Sense of rejection by mother because of gender; parents were foster carers but only fostered boys.
- Alleged sexual abuse perpetrated by half-brother from as early as four years old, until 16 years old.
- Alleged physical abuse by half-brother, included being thrown down the stairs in a suitcase. Half-brother's explanation for injuries allegedly always believed over Lisa's explanation.
- Half-brother admitted abusing Lisa's sisters, but not Lisa.
- Small and often physically ill – under care of paediatricians until 16 years old.
- Lisa alleges that when she disclosed the abuse at 12 years of age, her mother threatened that, if Lisa reported the abuse to the police, her parents would separate and lose their jobs, and it would 'kill' her grandmother.
- Not able to see father often as he worked away from home.

VIEW OF SELF, OTHERS, AND THE WORLD:

'Being worthless, not important, isolated, actively silenced, shoved about, and not listened to'.

Nobody can be trusted.

Everybody hurts me.

Whenever something good happens, it turns bad.

"How can people talk about Heaven and Hell when all I've had is Hell in this world?"

RULES FOR OWN BEHAVIOUR AND THAT OF OTHERS:

Do not have an opinion.

Do not trust others.

Do not let 'the real me' through.

Stay miserable so as not to 'fall so far'.

Scared to leave depression.

I will give my children a good start in life, and love.

CRITICAL INCIDENTS:

- Miscarriage of first child, at 24 th week of

pregnancy.

- Domestic violence in previous marriage, particularly incident in which a knife was held to her throat.
- Hormone treatment to aid conception between 1993 and 2002 – Lisa has questioned whether this had negative physical and emotional effects.
- Partner's arrest and trial.

A naturalistic study of 30 individuals experiencing non-epileptic seizures sought to identify predisposing, precipitating and perpetuating factors considered related to the seizures⁽³²⁾. In relation to predisposing and precipitating factors, 86.6% had experienced non-sexual trauma, 70% experienced social or family factors, 56.7% experienced bereavement, 30% had experienced sexual trauma and 13.3% had experienced physical health issues. Only 3.3% identified no predisposing or precipitating factors⁽³²⁾. Lisa could be said to have experienced each of these factors as either predisposing or precipitating factors in relation to the onset of PNES.

Incestuous sexual abuse may be associated with an increased risk of conversion disorder⁽¹⁾. Physical abuse in childhood has been associated with a larger amount of psychogenic symptoms^(36, 37), and bodily threat has been found to best predict somatoform dissociation⁽³⁸⁾. Family factors seen in Lisa's case have been linked to conversion disorder, including a lack of family cohesion⁽³⁹⁾ and low perception of maternal care⁽⁸⁾.

A high prevalence of adverse childhood experiences has been found to have a strong, graded relationship with high somatoform dissociation. In this case, these factors are combined with adverse later life events, thus supportive of the assertion that traditional unifactorial trauma-theories of conversion disorder should be replaced by multifactorial stress models⁽⁴⁰⁾.

Reuber et al.⁽²¹⁾ do not distinguish between the perpetuating factors identified among 30 participants with NES and 29 with 'other' functional neurological symptoms. However, across the sample of 59, 54.2% identified social or family factors and 42.4% experienced affective disorder thought to perpetuate their symptoms. Both factors were present for Lisa and could be considered as perpetuating factors.

SUMMARY OF CARE PLAN AND TREATMENT PACKAGE

The neurologist at the inpatient unit to where Lisa was admitted referred her to a local neurologist and also to secondary care adult mental health services. This led to her receiving outpatient psychiatric treatment and care from a community Continuing Support Team. The Psychiatrist referred her to the Acute Day Treatment Unit, details of which are outlined below.

THE ACUTE DAY TREATMENT UNIT AND SERVICE CONTEXT

The Acute Day Treatment Unit was based within a psychiatric unit. It offered care as an alternative to hospital or following hospital admissions. The Unit was multi-disciplinary and incorporated nurses, technical instructors (who provided group-based art therapy, relaxation and horticultural therapy), physiotherapists, a home economist, a complementary therapist and an assistant psychologist. The unit operated during weekdays and patients had individual care plans of attendance. Lisa attended over a nine-month period, initially for three days per week, gradually reducing to one day per week before discharge.

LISA'S GOALS ON ENTERING TREATMENT

Lisa had the following goals when she entered treatment: To 'get better, get rid of fits, get memory back, get on with the children, and go back to work'.

Lisa collaborated with staff at the Acute Day Treatment Unit to create a care plan that would meet her needs. There were eight salient assessed needs that the care plan aimed to address, as follows:

1. Ongoing assessment of needs. Given both Lisa's mental health and physical health needs, ongoing assessment was a priority. This was particularly true given Lisa's rapid changes in presentation as she responded to treatment and external influences.
2. Ongoing psychological intervention to work with Lisa regarding her conversion symptoms.
3. To enhance Lisa's coping skills, both psychological and physical.
4. To both assess and develop Lisa's active daily living skills.
5. To enhance self-esteem.
6. To develop physical abilities, particularly walking and the use of the left arm and hand.
7. To lift mood and provide distraction from negative thoughts.
8. To explore alternatives to day treatment, and support Lisa in achieving her aims.

Lisa was fully involved in the planning of her care throughout. Below, we outline the various aspects of treatment within the Acute Day Treatment Unit, with Lisa's comments about each.

LISA'S REFLECTIONS ON ELEMENTS OF HER CARE PACKAGE

1) MENTAL HEALTH

A) ACUTE DAY TREATMENT UNIT

I) GROUP WORK WITH THE TECHNICAL INSTRUCTORS

This included art, craft, clay and computer work. Sessions aimed to increase motivation, reduce anxiety, build confidence and self-esteem, improve concentration, enable expression of the self, encourage socialisation, and develop rewarding activity that could be continued post-discharge. Specific to Lisa, these sessions also aimed to encourage the use of her left-side (particularly her hand) in order to build muscular strength.

"I found this very beneficial due to building the strength in my left hand and also found mixed groups helped to socialise with others. It taught me the skills and ability to make things for family and friends, skills I could use at home to stop my mind wandering and to keep me focused. It built my self-esteem and helped me to take up new challenges. I was also helped by the encouragement I got, and feeling I was not being laughed at or made fun of."

II) COOKERY WITH THE HOME ECONOMIST.

These sessions aimed to develop existing skills, build confidence, promote awareness of healthy eating, and encourage meal-planning within a budget. Again, specific to Lisa, these sessions also aimed to encourage use of her left-side.

"The cookery helped me to adapt to doing what I could, as before my partner left I would let him do everything. I learned that I could cook healthy meals for the children on a budget. Seeing the children enjoy eating freshly prepared

healthy meals boosted my confidence.”

III) REFLEXOLOGY AND COMPLEMENTARY THERAPY

Lisa had weekly reflexology sessions, focusing on her feet. Reflexology is a type of massage that applies pressure to specific points of the feet to promote relaxation.

“I enjoyed this, as it seemed my time to relax and shut myself off to my daily problems. I learned how to relax and switch my brain off, which helped me at night to sleep.”

IV) PHYSIOTHERAPY

The physiotherapists provided exercises to improve Lisa’s gait, reduce her left-side weakness, and regain the use of her left-hand. Lisa also undertook work to help her control feelings of anxiety and panic. This included techniques to recognise an anxiety-provoking situation, remove herself from that situation, and engage in breathing exercises to regain feelings of control.

“The panic exercise helped me to control my breathing and this has made me feel I can take control of my own life again rather than my symptoms and illness controlling me. During physiotherapy, I learned how to take myself out of bad situations and calm myself down.”

V) WEEKLY INDIVIDUAL WORK WITH THE ASSISTANT PSYCHOLOGIST.

Four sessions were spent undertaking a detailed assessment of presenting problems and history, as well as setting goals, as described above. Three sessions then focused on developing a cognitive-behavioural formulation. Lisa was asked to keep a record of her seizures, which was monitored during sessions. It soon became apparent that the seizures occurred at times that Lisa felt increased levels of stress or tiredness. This recognition led to the work with the Physiotherapists to develop strategies to cope with increased stress. Following the assessment and formulation, the sessions were used to focus on depression, and particularly negative automatic thoughts.

“This helped me to look back over my life, which I can do now without the pain, guilt and blaming myself for other people’s actions. I now have a brighter outlook on life. The positive thinking helped so much and if I have a negative thought I can now turn it around and find a reasonable explanation for this.”

B) INTERVENTIONS FROM OTHER AGENCIES

I) THE JUNIOR DOCTOR

“I had felt that regular appointments would have been better. When I spoke to this person they made me feel like it was my fault and that they did not understand where I was coming from. When I needed a medication review this took a long time and I had lots of promises of change of medication and other treatments but they were spoken about at a meeting and then taken away because of funding.”

II) THE CONTINUING SUPPORT TEAM

“At the start I had a mental health Social Worker who I felt was out of her depth with my case. She went off sick a lot and every time I wanted support she was busy. I then had a Community Psychiatric Nurse (CPN) who was a great support and had a lot of time. She helped me to think things over myself. We had a good rapport.”

III) RESPITE CARE IN AN ‘ALTERNATIVE TO HOSPITAL BED’

In March 2006, it had become apparent that Lisa’s relationship was breaking down and there was a possibility that her partner would leave the family home. The professionals in the Continuing Support Team had significant concerns that being left as a single parent would have a negative impact on Lisa’s mental health and ability to cope. Consequently, respite care with mental health services was sought and obtained for a period of one week.

“When I went into respite in March 2006, I found it helpful because I was struggling at home and my partner would do everything for me and the children. Respite care gave me time to think things over and to make me get my independence back.”

2) PRIMARY CARE SERVICES

A) THE GENERAL PRACTITIONER (G.P.).

“My G.P. was very supportive and helpful. I had poor living conditions and she wrote on my behalf to support an application for Disability Living Allowance. The GP also wrote to my Junior Doctor requesting more support. I knew that if I needed anything my GP would always listen to me.”

B) THE HEALTH VISITOR

“My Health Visitor was supportive when I lost my memory as I found it hard to rebuild a relationship with my children, because I could not remember them. My Health Visitor got in touch with Home Start and this really helped me.”

3) PHYSICAL HEALTH SERVICES

A) THE NEUROLOGIST

“My Neurologist was good when I was transferred from one hospital to a specialist neurology ward to see what was wrong. When I had been told I had not got a neurological problem he still saw that I received psychological treatment.”

B) THE OUTPATIENT OCCUPATIONAL THERAPY DEPARTMENT

“This started in May 2005 after the first seizure and carried on until November 2005. They taught me how to adapt when I had my baby. As my left arm was no good, they taught me techniques to hold and feed her. After the second major seizure, they saw me until May 2006, and helped me learn to walk, hold things, and get my left side working. Later, the community Occupational Therapist helped in adapting my new house.”

C) THE PHYSICAL DISABILITIES SOCIAL WORK TEAM.

“The Physical Disabilities team were brought in too late, about two months after I came home from hospital. The team were supportive but if I was given more support earlier, I am sure my relationship would not have broken down. I feel that when the Physical Disabilities team did get involved they were very effective.”

4) FAMILY SUPPORT SERVICES

A) CHILDREN'S (SOCIAL) SERVICES

“I had a few different social work teams. The team I had initially was very supportive. I then changed to a Social Worker who I feel is prejudiced against mothers with mental health problems. I felt pushed into a corner and had to agree to share care of my daughter. I was told that if it went to court Social Services would back my ex-partner rather than myself, due to my mental health, even though my CPN had told them that I was doing really well.”

B) HOME CARE

“This helped me to learn basic skills such as cooking and doing things for the family, as well as helping with my self-care skills when I could not bathe alone because of mobility problems. I felt it would have been better during the day rather than the evening.”

TREATMENT OUTCOMES

Lisa made significant progress towards achieving the goals she had on entering treatment. Much of the literature focuses

on seizure frequency as the main outcome measure in the treatment of PNES, but this has been criticised and calls have been made for research to use a wider variety of outcome measurements, including socioeconomic status, overall level of functioning and other quality of life measures⁽²⁷⁾. Therefore, we include information about both seizure frequency and other outcomes.

Lisa monitored her seizures for a 39 day period during treatment. Having previously reported experiencing seizures up to four times per day before entering treatment, the frequency of seizures reduced on entering treatment to no more than three per week. These gradually reduced and by the time Lisa was discharged, she had ceased to experience seizures. She attributed this to her ability to identify situations as being stressful and likely to trigger a seizure, together with the use of coping mechanisms she had developed during treatment to either remove herself from or better cope with stressful situations. The absence of seizures in the presence of these new strategies appears to lend support to the hypothesis that the mechanism of the seizures was to protect Lisa from emotional distress. At the time of writing, Lisa has not had a seizure for nearly 24 months.

With regards to physical outcomes, Lisa made significant progress. The hemiparesis, gait difficulties and paralysis of her left hand that Lisa had demonstrated on admission were all resolved to the extent that they no longer impacted on her daily functioning.

Lisa reported a considerable reduction in symptoms of depression and a better ability to manage stress and anxiety. Lisa reported the return of some, although not all, of the memories she had lost following her experience of amnesia after the seizure that led to her admission to a neurological ward.

In relation to family relationships, Lisa continued to build a positive relationship with her children and avoided any further intervention from Children's (Social) Services. This could be seen as one outcome that could maintain the progress she had made, as the prospect of interventions from Children's (Social) Services had in the past proved to be a source of stress. Lisa went on to develop a new supportive relationship and later remarried.

Finally, Lisa demonstrated some positive social outcomes. At the time of writing, she had begun voluntary work and returned to college, with the intention of returning to paid work in the future. She also began leading an active social

life and developed a strong network of close friends.

Through regular review and evaluation, a date was planned to discharge Lisa from the Acute Treatment Unit, with appropriate continued support from community agencies and outpatient psychiatric appointments. Lisa worked to this date and there was no indication that she had become dependent on those involved in her care. Lisa continued to show what would be considered an expected level of engagement with her community psychiatric nurse, who was able to monitor Lisa's progress and any signs of relapse. Following Lisa had no relapse with regards to conversion symptoms. Sometime after discharge, she did experience an increase in symptoms of depression, but this was managed by the G.P. in the community.

DISCUSSION

We cannot be certain as to which factors were critical in contributing to Lisa's recovery to date. Here, we aim to highlight some of the hypotheses we developed together, as well as some of the lessons we learned from the case.

COLLABORATIVE APPROACH

It would be difficult to believe that the intensive care package Lisa received did not play a significant role in her recovery. It is reasonable to hypothesise that more general characteristics of the care package made a significant contribution to recovery. In line with the suggestion that staff should work to establish a therapeutic alliance and enable recovery with dignity⁽³⁾, the vast majority of staff worked in a genuinely collaborative manner with Lisa. Supportive, insight-oriented, cognitive and behavioural techniques were used to help Lisa develop understanding of her symptoms, consistent with the approach described by Cohen and Chang⁽¹⁴⁾. Lisa was fully involved in developing her care plan and understanding the goals of each treatment. It is thought that this collaborative approach worked by creating environments in which it was safe to change, and in which Lisa was encouraged to replace her symptoms with effective coping strategies. This is in line with the ethos of a process described by Daie and Witzum, who created situations which encouraged individuals to abandon their conversion symptom⁽⁴¹⁾.

Lisa had positive relationships with a number of the professionals involved. Following early life experiences of being actively silenced, Lisa was able to find validation from professionals who took the time to work through her difficulties, as well as intensifying support during 'crisis'

periods. It is worthy of note that Lisa found treatment most effective when she felt listened to and supported. This is in line with evidence in the literature about the importance of mental health professionals acknowledging symptoms as 'real' or 'genuine'⁽¹³⁾.

MULTIPLE INTERVENTIONS

Lisa happened to be referred to a unit in which multiple interventions were available for her to access simultaneously. It is acknowledged that the service itself was unusual in a climate of closure for many 'day services' in the UK and that many other individuals experiencing PNES may not have access to such a comprehensive package of multidisciplinary care.

It is also important to emphasise that research evidence demonstrates positive outcomes of single interventions, such as specific forms of psychotherapy^(19, 21), suggesting that multiple interventions may not be necessary. In addition, it was not possible to measure the effectiveness of each intervention. It is possible that Lisa would have experienced similar outcomes without receiving such an intense package of treatment, particularly given changes in social circumstances that she experienced during the period of care. However, from both a patient and professional perspective, the multidisciplinary nature of the care package appeared to be highly valuable in addressing each of Lisa's identified clinical needs.

One of the significant outcomes in Lisa's case was the improvement that she made in relation to improving her physical ability and overcoming impairments that she had demonstrated on admission. It is hypothesised that work with the physiotherapists and Home Economist, which focused on the development of both gross and fine motor skill tasks, was fundamental in contributing to the positive physical outcomes and a key benefit of a multidisciplinary approach in meeting Lisa's needs. Further research into outcomes other than seizure frequency might offer further insights into the potential needs and outcomes of those who experience PNES alongside other difficulties, including physical disability, and serve to develop understanding about when a multidisciplinary approach may or may not be either necessary or appropriate.

With the wide range of factors that are thought to contribute to conversion symptoms it must be remembered that, for each patient, there is likely to be a broad contextual background to difficulties as well as a complex presentation of a range of symptoms⁽³⁾. Given this, it is perhaps not

surprising that none of the treatment options have yet emerged as an exclusive treatment of choice⁽¹⁶⁾. It seems reasonable to hypothesise that the combination of physical, psychological and pharmacological treatments contributed to Lisa's recovery. The case seems to offer clinical support to the assertion that cognitive-behavioural work should be combined with physiotherapy, as well as pharmacotherapy⁽³⁾.

COGNITIVE-BEHAVIOURAL THERAPY

Giving Lisa the opportunity to develop a psychological formulation seemed to contribute to her both understanding and regaining control over her experiences. Actively using the available literature on conversion disorder appeared particularly valuable in terms of thinking about possible predisposing and precipitating factors when developing the formulation.

The cognitive framework allowed the conversion symptoms to be viewed as a defensive function that protected Lisa from overwhelming affect⁽⁴⁾. This helped to offer an alternative to the possible view that Lisa's symptoms were manipulative or exaggerated⁽³⁾. It also helped to directly inform the care plan, as Lisa was supported to recognise situations that were likely to induce overwhelming affect, remove herself from them and practice alternative coping strategies to reduce conversion symptoms. Developing the skills to manage intrapsychic conflict and anxiety⁽⁴⁾ appeared to be fundamental to reducing the frequency of Lisa's seizures, as well as boosting her confidence and sense of control.

LISA'S APPROACH TO TREATMENT

There can be no doubt that Lisa's own motivation contributed significantly to her recovery. A care package of this intensity would have failed had she not been motivated to fully engage with each of its components. Such care brings with it a certain amount of pressure, and demands a high level of commitment. It is possible that other individuals with similar difficulties may not have the same level of motivation. The implications of this are that working to increase the individual's motivation may be a valuable investment of time and resources, for example through the use of motivational interviewing⁽⁴²⁾.

EXTERNAL CIRCUMSTANCES AND LIFE EVENTS

During the course of Lisa's treatment, her partner left the family home. Although this led to a crisis period in terms of her depression and difficulties relating to the care of the children, we believe that it had a significant impact on

accelerating her recovery. It must be acknowledged that Lisa is clear that it was this event – as opposed to any element of the treatment package – that led her to become more independent more quickly, possibly as she was not longer able to experience the 'secondary gains' that had previously maintained or strengthened her symptoms⁽⁵⁾. Lisa describes systemic reinforcement of both conversion symptoms and depression; her partner was exceptionally supportive during the initial stages of her illness, and did everything that she said she could not. It is possible that psycho-educational work with Lisa's partner may have helped him to encourage her to do more earlier, as well as encouraging her to recognise and reward her strengths, rather than allowing her to take a 'patient' role. It is possible that family therapy would have been beneficial, as it is for many families who have invested heavily in supporting their family member with their neurological difficulties⁽³⁾.

This is not to suggest that Lisa could have done everything, as her symptoms were debilitating and impacted on her mobility. However, she acknowledges that she allowed her partner to carry out small tasks that she could have achieved herself. It is these lower-level tasks that systemic work could look to address initially, as well as more general issues around the roles and expectations of both parties. In hindsight, Lisa's partner may well have benefited from being involved in the psycho-educational work undertaken with Lisa, in order to develop his understanding and offer him support in the role of primary carer. In hindsight, it seems obvious that one lesson for professionals might be to routinely assess and work to meet the needs of the carer as an intrinsic part of the care package.

Lisa strongly believed that her partner's trial for harassment played a significant role in contributing to the onset of her symptoms. She felt that this hypothesis was supported by her experience following her partner being found 'Not Guilty', when memories began to return. Although on reflection it appeared to be a huge oversight, the impact of these events was not recognised until the verdict was reached. Lisa was able to discuss these events with professionals, but they should perhaps have received more focus as precipitating stressors.

The lessons in relation to systemic issues in this case are particularly important to consider in relation to the emerging evidence base for the use of cognitive-behavioural⁽¹⁹⁾ or tailored individual psychotherapy⁽³²⁾. While such approaches may lead to positive outcomes for a significant number of

individuals, they are likely to neglect systemic issues that could contribute to the maintenance of symptoms. Although Lisa's familial circumstances were perhaps more complex than most individuals', the importance of considering the patient's systemic context in any treatment of PNES is highlighted.

CHALLENGES OF IMPLEMENTING THE CARE PACKAGE

There were certainly areas in which professionals could have improved the services offered. On occasion, for example, discussions about budgets were held in Lisa's presence, making her feel devalued as an individual. At times, there was a sense of a lack of co-ordination between agencies involved. On reflection, this was probably indicative of trying to organise so many contributors – and agendas – in the planning and implementation of the care package. There was a need to balance Lisa's physical and mental health needs in her interest, together with the protection of the best interests of her children. Each of the professionals involved had different priorities with regards to meeting these needs, dependent upon their profession or the agency they represented. At times, this could feel overwhelming and uncontained for the professionals involved.

In addition to general issues relating to communication, it is important to consider the way in which different professionals understood and operationalised Lisa's difficulties. The majority of professionals involved had very little experience of working with individuals with PNES or knowledge of the available literature at the time of Lisa's admission to the service – it was far from a specialist treatment unit for PNES. The Assistant Psychologist and Lisa worked through some of the available literature to develop an understanding about PNES in terms of theoretical understandings of etiology and management. This information was shared with the professionals involved, both within the treatment unit and also those from other agencies.

There were some specific instances in which there was clearly a shared understanding that informed interventions, such as the physiotherapists basing their interventions on the psychological formulation regarding likely triggers for a seizure. However, Lisa's reflections indicate that she did not perceive all professionals to share this understanding and, in some cases, felt blamed or discriminated against. Given the importance to patients of being listened to and accepted as needing ongoing support for 'genuine' symptoms⁽¹⁰⁾, perceptions of staff attitudes could significantly influence

patient care.

While multidisciplinary or multiagency working may have distinct advantages⁽⁴⁾, Lisa's case highlights the importance of establishing clear channels of communication to co-ordinate care, as well as the importance of a shared understanding of PNES. Training for professionals PNES may be useful in working towards a shared understanding and approach, as less training has been associated with negative attitudes⁽¹²⁾.

LIMITATIONS

It would have been preferable to have some measures of outcomes to support the present case study. Psychological outcome measures, such as scales of depression, could have offered a useful gauge of progress over time, as well as measures such as diaries of frequency of seizures throughout the course of treatment, rather than a selected period. This would have helped to evaluate the overall effectiveness of the care package and we recognise that their absence is a significant limitation.

CONCLUSION

This case provides an example of a multi-disciplinary and integrative package of care, which aimed to work in the interests of Lisa. It is hoped that this study can help both professionals and individuals with conversion symptoms in thinking about how to approach the potential complexities of treatment.

References

1. Soares ND, Grossman L: Somatoform disorder: conversion. 2005; Retrieved on 09.03.06 from: <http://www.emedicaine.com/ped/topic2780.htm>.
2. American Psychiatric Association: Diagnostic and statistical manual of mental disorders, 4th ed, Text Revision: DSM-IV-TR®. 1995; Washington, DC: Author.
3. Owens C, Dein, S: Conversion disorder: the modern hysteria. *Adv Psychiatr Treat*; 2006; 12: 152–157.
4. LaFrance Jr. WC, Barry JJ: Update on treatments of psychological nonepileptic seizures. *Epilepsy Behav*; 2005; 7: 364 – 374.
5. Schwartz AC, Calhoun AW, Eschbach CL, Seelig BJ: Treatment of conversion disorder in an African American Christian woman: cultural and social considerations. *Am J Psychiatry*; 2001; 158: 1385–1391.
6. Devinsky O, Mesad S, Alper K: Nondominant hemisphere lesions and conversion nonepileptic seizures. *J Neuropsychiatry Clin Neurosci*; 2001; 13: 367–373.
7. Goldstein LH, Deale AC, Mitchell-O'Malley SJ, Toone BK, Mellers JDC: An evaluation of cognitive-behavioural therapy as a treatment for dissociative seizures: a pilot study. *Cogn Behav Neurol*; 2004; 17(1): 41 – 49.
8. Stone J, Sharpe M, Binzer M: Motor conversion symptoms and pseudoseizures: a comparison of clinical characteristics. *Psychosomatics*; 2004; 45:492–429.
9. Carson AJ, Stone J, Warlow C, Sharpe M: Patients whom

- neurologists find difficult to help. *J. Neurol Neurosurg Psychiatry*; 2004; 75: 1776 – 1778.
10. Nettleton S. 'I just want permission to be ill': Towards a sociology of medically unexplained symptoms. *Soc Sci Med*; 2006; 6: 1167 – 1178.
11. Stone J, Colyer M, Feltbower S, Carson A, Sharpe M: "Psychosomatic": A systematic review of its meaning in newspaper articles. *Psychosomatics*; 2004; 45(4): 287 – 290.
12. Ahern L, Stone J, Sharpe MC. Attitudes of neuroscience nurses toward patients with conversion symptoms. *Psychosomatics*; 50: 336 – 339.
13. Thompson R, Isaac CL, Rowse G, Tooth CL, Reuber M: What is it like to receive a diagnosis of nonepileptic seizures? *Epilepsy Behav*; 2009; 14: 508 – 515.
14. Cohen LM, Chang K: Comorbid factitious and conversion disorders. *Psychosomatics*. 2004; 45:243–246.
15. Moene FC, Hoogduin KAL, Van Dyck R: The inpatient treatment of patients suffering from (motor) conversion symptoms: a description of eight cases. *Int J Clin Exp Hypn*; 1998; 46:171–190.
16. Wald J, Taylor S, Scamvougeras A: Cognitive behavioural and neuropsychiatric treatment of post-traumatic conversion disorder: a case study. *Cogn Behav Ther*; 2004; 33:12–20.
17. Reuber M, Elger CE. Psychogenic nonepileptic seizures: review and update. *Epilepsy Behav*; 2003; 4: 205 – 216.
18. Brooks JL, Goodfellow L, Bodde NMG, Aldenkamp A, Baker GA: Nondrug treatments for psychogenic nonepileptic seizures: what's the evidence? *Epilepsy Behav*; 2007; 11: 367 – 377.
19. Goldstein LH, Chalder T, Chigwedere C, Khondoker MR, Moriarty J, Toone BK, Mellers JDC: Cognitive-behavioural therapy for psychogenic nonepileptic seizures. *Neurology*; 2010; 74(24): 1986 – 1994.
20. Howlett S, Reuber M: An augmented model of brief psychodynamic interpersonal therapy for patients with nonepileptic seizures. *Psychotherapy (Chic)*; 2009; 46(1): 125 – 138.
21. Reuber M, Burness C, Howlett S, Brazier J, Grünewald R: Tailored psychotherapy for patients with functional symptoms: a pilot study. *J Psychosom Res*; 2007; 63: 625 – 632.
22. LaFrance Jr. WC, Miller IW, Ryan CE, Blum AS, Solomon DA, Kelley JE, Keitner GI: Cognitive behavioural therapy for psychogenic nonepileptic seizures. *Epilepsy Behav*; 2009; 14: 591 – 596.
23. LaFrance Jr. WC, Keitner GI, Papandonatos GD, Blumm AS, Machan JT, Ryan CE, Miller IW: Pilot pharmacologic randomized controlled trial for psychogenic nonepileptic seizures. *Neurology*; 2010; 75(13): 1166 – 1173.
24. Shapiro AP, Teasell RW: Behavioural interventions in the rehabilitation of acute v. chronic non-organic (conversion/factitious) motor disorders. *The Br J of Psychiatry*; 2004; 185:140–146.
25. Viederman M: Metaphor and meaning in conversion disorder: a brief active therapy. *Psychosom Med*; 1995; 57:403–409.
26. LaFrance Jr. WC, Devinsky O: Treatment of nonepileptic seizures. *Epilepsy Behav*; 2002; 3: S19 – S23.
27. Durrant J, Rickards H, Cavana AE: Prognosis and outcome predictors in psychogenic nonepileptic seizures. *Epilepsy Res Treatment*; 2011; Article ID 274736, 7 pages: Doi: 10.1155/2011/274736.
28. McKenzie P, Russell A, Pelosi A, Duncan R: Early outcomes and predictors in 260 patients with psychogenic nonepileptic attacks. *Neurology*; 2010; 74(1): 64 – 69.
29. Carton S, Thompson PJ, Duncan JS: Non-epileptic seizures: patients' understanding and reaction to the diagnosis and impact on outcome. *Seizure*; 2003; 12: 287 – 294.
30. Stone K, Zeman A, Sharpe M: Functional weakness and sensory disturbance. *J Neurol Neurosurg Psychiatry*; 2002; 73: 241 – 245.
31. Mellers JDC: The approach to patients with "non-epileptic seizures". *Postgrad Med J*; 2005; 81: 498 – 504.
32. Reuber M, Howlett S, Khan A, Grünewald R: Non-epileptic seizures and other functional neurological symptoms: predisposing, precipitating, and perpetuating factors. *Psychosomatics*; 2007; 48(3), 230 – 238.
33. Goldstein LH, Mellers JDC: Ictal symptoms of anxiety, avoidance behaviour, and dissociation in patients with dissociative seizures. *J Neurol Neurosurg Psychiatry*; 2006; 77: 616 – 621.
34. Mellers JDC: The diagnosis and management of dissociative seizures. 2009; Retrieved on 01.03.11 from: <http://www.epilepsysociety.org.uk/Forprofessionals/Articles-1/Differentialdiagnosis>
35. Baslet G: Psychogenic non-epileptic seizures: a model of their pathogenic mechanism. *Seizure*; 2011; 20: 1 – 13.
36. Roelofs K, Keijsers GPJ, Hoogduin KAL, Naering GWB, Moene FC: Childhood abuse in patients with conversion disorder. *Am J Psychiatry*; 2002; 159:1908–1914.
37. Perez MJ: Defense mechanisms and family dynamic characteristics of patients with nonepileptic and epileptic seizures. *Dissertation Abstracts International: Section B: The Sciences and Engineering*; 1998; 58, no. 10-B.
38. Nijenhuis, ERS, van der Hart O, Kruger K, Steele, K: Somatiform dissociation, reported abuse and animal defence-like reactions. *Aust N Z J Psychiatry*; 2004; 38:678–686.
39. Brown RJ, Schrag A, Trimble MR: Dissociation, childhood interpersonal trauma, and family functioning in patients with somatization disorder. *Am J Psychiatry*; 2005; 162: 899–905.
40. Roelofs K, Spinhoven P, Sandijck P, Moene F, Hoogduin KAL: The impact of early trauma and recent life-events on symptom severity in patients with conversion disorder. *J Nerv Ment Dis*; 2005; 193:508–514.
41. Daie N, Witzum E: Short-term strategic treatment in traumatic conversion reactions. *Am J Psychother*; 1992; 45:335–347.
42. Arkowitz, H, Westra, H A, Miller, W R & Rollnick, S: Motivational interviewing in the treatment of psychological problems. 2007; New York: Guildford Press.

Author Information

Anna C Tickle, BSc., MSc., ClinPsyD

Clinical Psychologist, Nottinghamshire Healthcare NHS Trust

Helena Crockford, BSc., Dip Clin Psych

Consultant Clinical Psychologist, Norfolk and Waveney Mental Health NHS Foundation Trust