

The cost of everything and the value of nothing*: Nursing case histories

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A series of three nursing case histories related to epilepsy care are presented to demonstrate the range of clinical nursing activity in an epilepsy clinic and to pose the question whether any of these activities, deemed essential by both clinician and nurse, would be thought appropriate if cost effectiveness of nursing care was merely measured by a significant reduction in seizure frequency. The conclusion drawn is that a specialist epilepsy nurse in an epilepsy clinic is an invaluable member of the team, who frees the medical member of the team to concentrate on those duties which need medical input: but, using currently applied outcome criteria, it would be difficult to justify the nurse's cost effectiveness. Measures that do this accurately and fairly must be developed.

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INTRODUCTION

In this issue of 'Seizure' the proceedings of a day long meeting related to epilepsy nursing ('essential colleague or disposable handmaiden') are presented¹. Neither of us were surprised at the vehement and angry response that nurses made, in this meeting, to the suggestion from their colleagues in social science and public health that there was very little evidence to show that epilepsy nurses had any effectiveness in managing epilepsy particularly if the outcome criteria of a significant reduction in seizure frequency was applied (this does seem to be the only criteria presently used by public health doctors assessing the need for specialist epilepsy services). We present three case histories to suggest that this criteria (of use in assessing medical performance) undervalues the role of the specialist epilepsy nurse.

CASE 1: MARY

Mary is 28 and lives in a deprived part of our city. She had an unhappy childhood with emotional and

physical abuse and, although intelligent, did poorly at school and has not worked since, living on benefit. She lives with a partner who is a drug addict and who sometimes beats her. She has also, from time to time, used illicit drugs, although she is not drug dependant.

She is chronically unhappy and anxious with multiple somatic symptoms including dizziness, headache, multiple aches and pains and poor sleep: she is supported by a local mental health team particularly after attempts at suicide.

She also has undoubted Juvenile Myoclonic Epilepsy, starting to have early morning myoclonic jerks at the age of 14 and then tonic-clonic seizures. She is also photo sensitive. Previous attempts by other services to try to bring her epilepsy under control have been fruitless. Initially she was treated with sodium valproate and then lamotrigine, but she withdrew herself from both medications because of 'unbearable side effects'.

When referred to a nurse practitioner (LG) she was using large quantities of clobazam in a very erratic manner, which was exacerbating her seizures rather than controlling them. It was clear on the nurse's first assessment that Mary had very negative cognitions

*'nowadays people know the price of everything and the value of nothing'—Oscar Wilde

both about doctors (whom she claimed to have totally failed her and ruined her life because of their inability to control her seizures) and also about herself and the effect of medication. She declared that any new medication would only give her side effects, and would not control her seizures. It was clear to the nurse that what she was describing as side effects were her multiple somatic symptoms, related to her anxiety problems but Mary resolutely refused to try either sodium valproate or lamotrigine again.

The nurse therefore saw Mary on a weekly basis to try to establish a relationship (her psychiatric care continued in the local mental health unit) and to build up trust and then initiated a very slow introduction of Levetiracetam (initially 250 mgs a day) increasing the dose very slowly over the next few months and continuing with weekly visits.

Because the nurse had established some trust with the patient she was able to steer her through the process of gradual escalation of the Levetiracetam and was able to point out that the side effects that the patient complained of at each dose increment were, in fact, the same ones that she was complaining of before the treatment process started. On a comparatively small dose of Levetiracetam the patient's morning jerks stopped as did her tonic-clonic seizures and she was able to tolerate the drug. The nurse then began the process of gradually weaning her off Clobazam by slow, small (5 mg) reductions in its dose every fortnight and increasing the dose of Levetiracetam to cover this withdrawal, where necessary.

As a result of this slow treatment process the nurse was able to keep the confidence of the patient and the patient is now seizure free and no longer has negative cognitions about the medication she is taking and has a more positive attitude to her future, planning to eventually undergo some formal training and being able to work. Her mental state has also improved and she is seeking new accommodation. This satisfactory therapeutic outcome has been achieved by weekly outpatient sessions (which have now become fortnightly and will soon become monthly) and common sense cognitive therapy.

COMMENT

Developing a therapeutic relationship, which was necessary to manage positive change in this patient, is something difficult to quantify or measure. It involved a kind of common sense cognitive therapy and the development, for a while, of a firm but permissive parental relationship with the patient. It has also involved covert prescribing: although the nurse was making the adjustments to drug dosage the prescription had to be signed by a doctor—even

though there were frequent changes in prescription and initially prescriptions for no more than a week at a time were issued (because of the Mary's propensity to overdose). It would, of course, be much better if the nurse was able to prescribe herself (a point that will be discussed at the annual scientific meeting of the International League Against Epilepsy, British Branch, in Exeter in April 2002).

This is an example of where, perhaps, seizure reduction as the main method of measuring effectiveness would be appropriate, because Mary was not seizure free and now is (although the cost of getting her seizure free—apart from the drug costs—was considerable and required a great deal of time and attention). This is a task that a junior doctor would not have been able to undertake because junior doctors do not stay in a post long enough (even if they have the requisite skills when they arrive) to effect a slow change like this: arguably a senior doctor could have achieved the same result (assuming that he or she had the same nurturing and parenting skills that the nurse has) but the cost would have been even higher.

CASE 2: RAJINDA

Rajinda is 22 and works in her family shop. One morning, when turning around quickly to help a customer, she struck the point of her elbow sharply on the till in the shop and felt intense pain: she lost consciousness and dropped to the floor where she lay pale and still. Her distraught family immediately picked her up: she stiffened and convulsed but swiftly recovered when laid on the floor again. Within a couple of minutes she was able to sit up, although feeling a little dizzy, immediately knew where she was, had not injured herself, had not bitten her tongue and had not been incontinent. Her general practitioner who lived near by was summoned to the scene and had her admitted to casualty: he told the family that she had had an epileptic seizure.

She was seen three weeks later in our fast-track new onset seizure clinic by the specialist nurse (LG) acting in a triage role. Having been able to interview both patient and a reliable witness, the nurse was able to make the decision that this was not an epileptic seizure but was syncope and that the convulsion was due to the distraught parents making the understandable mistake of lifting her straight off the floor. The nurse performed an ECG (even though there had been no previous history of fainting) which was normal, and made the clinical judgement that there was no need to institute other investigations such as an EEG or MRI scan and discharged the patient.

COMMENT

We could discuss whether such a clinical decision is within the competence of a nurse (a point also to be discussed in the next ILAE British Branch scientific meeting) but it is our clinical judgement that it is, a judgement based on careful audit of the nurse's triage role².

She was trained in her role by initially sitting in on a consultant (TB) led triage clinic. After three months she then started working in partnership with the consultant and after a further three months began running her own triage clinic, but reviewing the patients with the consultant before making a final decision. Latterly she has not needed immediate supervision of her decisions but medical help and advice is immediately available if needed. The nurse can, at her own discretion, arrange for the patient who has been reviewed by her to have EEG, ECG or MRI investigation. Patients who are thus investigated are reviewed by the nurse and consultant together at a later appointment.

We reviewed the notes of patients seen in the clinic by the nurse practitioner over a 6 month period looking at the initial diagnosis she made and the final diagnosis made and the number of investigations undertaken.

Over a 6 month period 62 patients were referred and seen by the nurse in the triage clinic, all within a month of referral. 44% were seen for new onset seizure assessment (most of whom had been diagnosed with epilepsy by their GP). The remaining 56% of the patients, new to our service, were referred for an urgent review of existing epilepsy.

In those patients with 'existing epilepsy' 11% were diagnosed as not having epilepsy: she confirmed the diagnosis as epilepsy in the remaining 89%. (Consultant review confirmed the nurse's diagnosis: the only disagreement between consultant and nurse related to two changes in seizure classification). Half of these 'existing epilepsy' patients had subsequent MRI scans and 31% had subsequent EEG investigation. In the remainder it was felt by the nurse (and confirmed by the consultant) that a management plan could be developed without recourse to further investigation (had these patients been sent to our usual one-stop clinic they would have received the investigations whether or not they actually needed them).

In those patients referred with new onset seizures, most of whom who had been diagnosed as having epilepsy by the GP, as in Rajinda's case, 63% were found not to have epilepsy: in 22% the diagnosis was uncertain: only 15% were diagnosed by the nurse as having definite epilepsy. Of those with non-epilepsy 30% were given the diagnosis of syncope. All these diagnoses, including that important group of patients where diagnosis remains uncertain and who have to be

followed up until the diagnosis does become certain, were confirmed by consultant review.

It would seem that a nurse-led triage clinic with the nurse being able to make independent clinical decisions about whether or not to institute investigation or follow up has been a success. There has been no disagreement between nurse and consultant over diagnosis or management plans and there has been a significant saving in investigation costs, both EEG and MRI. A very few patients were disgruntled at seeing a nurse rather than a doctor at first, but good interviewing techniques relieved the disgruntlement and most patients eventually found it easier to unburden themselves to a nurse rather than to a doctor.

The nurse therefore has made an apparent significant saving in cost. But since, as in Rajinda's case, if the patient does not have epilepsy it would be difficult to measure her effectiveness purely by measuring whether or not she had reduced seizure frequency since the patient is unlikely to have another seizure and if she does it will not be an epileptic one! with strict economics one could even argue that her role has had a negative effect since the service receives payment from the purchaser for EEGs and MRIs: actually reducing the frequency of these investigations reduces the income of the unit. This paradox of purchasing (not uncommon the British National Health Service) needs to be resolved and is a product of the inflexible nature of NHS financing. Clinically we feel the introduction of a nurse into the triage service (which, again, frees up the consultant for other duties) has been of benefit and the task could not be done by an inexperienced junior doctor—by the time he or she was trained they would have left the service. It is a clinically effective use of the nurses time. How do we prove this to our financial masters?

CASE 3: SUSAN

Susan has juvenile myoclonic epilepsy which began at the age of 14 and was effectively controlled with sodium valproate 2 g total daily dose: she was followed up by her general practitioner. She married and wishing to have children asked her general practitioner if the drug she was taking was safe in terms of having children and whether she should take other precautions. She was informed that the drug was 'as safe as any other' and that there was no evidence that she need to do anything else.

Perhaps fortuitously she failed to become pregnant after 3 years of unprotected intercourse and was referred to a local women's clinic, with whom our epilepsy nurse (LG) has a liaison role.

Investigation showed that the woman's infertility was related to the Polycystic Ovary Syndrome which

we felt was probably (but not certainly) related to the sodium valproate she had been taking for many years. She had had some weight gain, a degree of hirsutism and had the characteristics of the Polycystic Ovary Syndrome on both ovarian scanning and on measurement of her ovarian hormones: she also had very irregular menstruation.

It was therefore suggested, by both nurse and consultant together, that the patient should withdraw from the sodium valproate, but because she had juvenile myoclonic epilepsy would need to substitute this for lamotrigine. She was warned, firstly, that although she appeared to be infertile our experience was that adding in lamotrigine to somebody also taking valproate sometimes led to unexpected pregnancies and that she would therefore need to restart contraception: secondly the switch from valproate to lamotrigine is a long slow process, particularly because she was seizure free, and, for obvious reasons, would wish to remain seizure free.

She therefore was enrolled in the nurse's switch clinic. Lamotrigine was slowly added in and then valproate very slowly withdrawn according to our clinic schedule³. At the same time she had to be encouraged to continue to use contraception (something she found difficult to accept because of her unhappy experience of 3 years unprotected but unproductive intercourse). When the valproate began to be withdrawn she needed a great deal of support and encouragement because of her fear of having further seizures. This necessitated not only monthly clinic visits plus blood level and EEG monitoring (which we have found to be useful in the switch process, particularly with patients with primary generalised epilepsy⁴) but also weekly telephone calls to calm her anxiety.

During the course of the withdrawal a degree of photosensitivity briefly returned needing a further increase in lamotrigine dose (which had to be explained to the patient) but she finally withdrew from valproate. Before she had done so her periods had returned to normal and her hormone levels had returned to normal and she was able to remain seizure free on lamotrigine alone. As soon as she abandoned contraception she became pregnant. She needed a great deal of support during the pregnancy because of her anxieties about seizures during pregnancy, and during labour: monitoring of her EEG and blood levels were needed to continue to keep her seizure free. As is usual with lamotrigine dose increases had to be made during the pregnancy⁵ and the dose then dropped almost immediately in the puerperium as neurotoxic side effects kicked in.

She now has a normal baby and has remained seizure free and is contemplating a further pregnancy. She was also encouraged to take folic acid 5 mg daily

before she conceived which she agreed to do. All the support, monitoring and drug change was nurse led.

COMMENT

This is an example of the role of the nurse in the pre-conception clinic. Again, necessary drug changes are made by covert prescribing and the successful outcome of this case was heavily dependant on the time that the nurse spent in explaining, supporting and counselling the patient in addition to the medical tasks of arranging EEG investigations and blood level monitoring.

We both feel this is a very important role for a nurse in a clinic such as ours. The work is carried out unsupervised, except for consultant support if needed. It has involved a great deal of nurse time but since the patient was seizure free to start with, trying to measure the nurse's effectiveness by recording significant improvements in seizure frequency is meaningless. If the patient had developed seizures during the switch process this might have been a more appropriate, if negative, measure. If the patient had been left on valproate and given clomiphene to induce ovulation and subsequently had had a spina bifida baby (with the resultant enormous financial cost to the state) this would not have entered into any equation in terms of measuring the nurse's efficacy in the clinic in which she works. Saving money may be seen as efficient in managers, but not in nurses!

DISCUSSION

We have tried to show the wide ranging roles that a trained epilepsy nurse plays in an epilepsy clinic. We have also tried to show that the value of much of what she does would go completely unrecognised by the present method of assessing a nurse's work and we would encourage the development of a better way of assessing the effectiveness of a nurse in epilepsy care. Our joint view is that the nurse/consultant role is a partnership: each bring different skills to the management of patients with epilepsy, but they work together as a team and neither role is more important than the other. An effective and harmonious team brings enormous job satisfaction: but job satisfaction is something not measured in our present health service, although it almost certainly has an important and incalculable role in improving patient care.

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