Beyond the Protocol: The Potential of Person Centred Care - GS Baron

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Curriculum vitae

Geoff Baron obtained the MBChB at UCT in 1985. He completed his internship at Groote Schuur Hospital and then did two years of National Service in the SADF. He has since completed the Vocational Training rotation at Frere Hospital and is registered at MEDUNSA as a part time student for the MPrax Med degree. His interests include Health Resource utlisation and patients' perceptions of quality of care. He is married to Ceri and they have two children.

Summary

A patient report is given of a young, poorly supported father with recurrent seizures who was helped by a caring, person-orientated physician. If the traditional disease-orientated approach had been used, many potential avenues of help would have been unexplored. The value of applying some of the primary principles in family medicine is illustrated by following this patient's history.

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Epilepsy; Patient Report; Physician-Patient Relations; Person-centred Approach.

Introduction

Two of the primary principles of Family Medicine are that the Family Physician is committed to the person rather than to a specific body of knowledge or group of diseases, and that the Family Physician will strive to understand a patient's problem in its proper context.[1]

I believe that the following patient illustrates the importance of applying these principles at all times and explores the possibility of individual person-oriented care that can be at a level above that confined by a rigid, general, disease-oriented protocol.

An Individual Patient with Recurrent Seizures

Hopefully this example will illustrate the importance of tailoring therapy for the individual patient and of being patient-centred in one's approach.

S is a 36 year old Xhosa man who suffers from recurrent seizures despite being compliant on drug therapy. I have treated him for over two years for both his seizures and other ailments that have afflicted him and his family during this period.

We first met when S was referred to me by one of the nurse-practitioners at our clinic for review of his anti-convulsant drug therapy. He was labelled a "problem case" as he was having recurrent seizures despite therapeutic serum levels of carbamazepine.

S had an almost perfect attendance record at our clinic and his record revealed that he experienced, on average, one to three seizures per month despite apparent compliance on medication. He was currently on carbamazepine having not achieved seizure control on phenobarbitone in the past despite achieving serum levels of the drug that were consistently in the therapeutic range.

I was taken aback, initially, by the number and frequency of seizures that were occurring despite compliance with an appropriate drug regimen. I took a long history and managed to interview an eye witness who had seen several of S's seizures. I was satisfied that he was indeed having seizures. It appeared that the seizures were partial with evolution to being tonic-clonic in nature. They lasted less than five minutes on average and were preceded by a constant warning symptom of feeling "dizzy" for a short period prior to the seizure. S was thus able, by acting promptly, to remove himself from

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any impending danger just prior to a seizure.

The seizures themselves were tonic-clonic in nature and were often associated with tongue biting but rarely with incontinence. There was a period of post-ictal confusion and drowsiness that followed the seizures. No obvious immediate trigger factors such as alcohol, exhaustion or visual stimuli could be found.

S did not have any history of birth trauma, head injury, previous meningitis or childhood seizures. I examined him carefully and found no neurological (or any other) abnormality at all. There were, also, no signs of long term anti convulsant drug (ACD) side effects.

A visit to his home and to his employer

S had been having seizures for about eight years by the time I met him. It is reasonable to conclude that he must have suffered in the region of 100 seizures in all in this period.

Amazingly, S had a reasonable job and an intact family. He worked at a local nursery and had done so for the past six years. He was considered a valuable part of the team there as he had an excellent knowledge of plants and how to grow them. His employer was aware of his seizures but claimed that they were not an insurmountable problem. He certainly valued S sufficiently to not consider asking him to leave. He was aware that S's seizures were an inconvenience but knew how to handle them in the acute situation. He did not dock any pay or leave for time off (having seizures) and was quite prepared to help with transport to the clinic or hospital. The rest of the staff at the nursery had been instructed on how to deal with a seizure in a first aid situation and there was apparently no panic engendered by a seizure at the workplace.

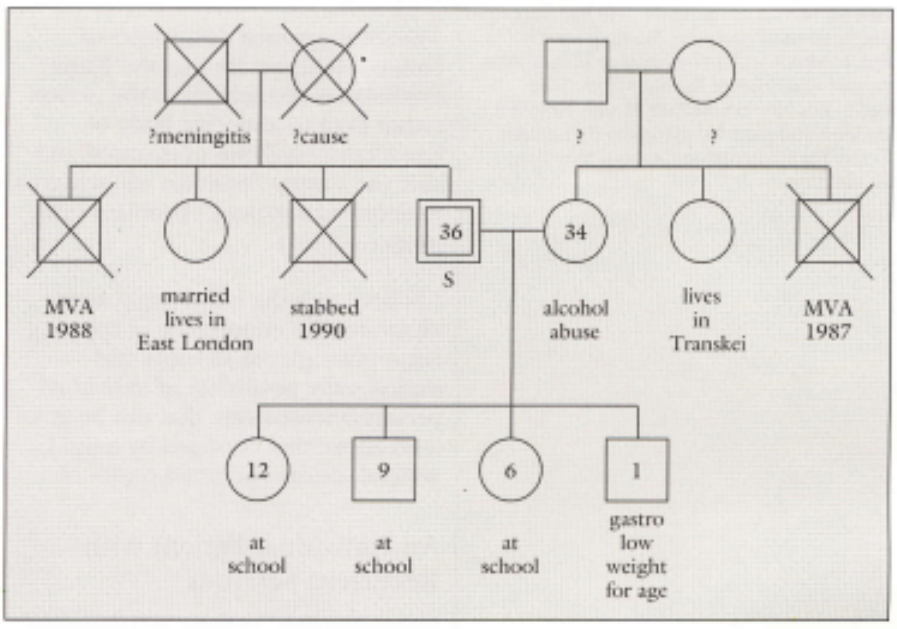
S was married with four children (see genogram) and the family lived in a small house on the nursery premises along with most, if not all, of the other workers and their families. They also had a second home in a rural district where his wife's family lived. His family lived close to this second "weekend" home.

Genogram

The marriage was a stressed one as S's wife drank heavily and, as a result, did not always care properly for the children. This distressed S greatly and he often expressed his feelings of anger and frustration in this regard. He claimed that he, on occasions, had to arrange for their neighbours to take care of his younger children while his wife was out drinking. In fact, during the course of our relationship, it was once necessary to admit their youngest child for intravenous therapy for gastro-enteritis and low weight for age. On this occasion the child was brought to the hospital by S's sister.

I initially increased the dose of S's carbamazepine to a total of 1 000 mg/day in three divided doses (previous dose 800 mg) despite the therapeutic serum levels. After this change his serum levels remained in the upper therapeutic range and he continued to have seizures.

At this stage I subjected S to a number of investigations to look for a



Genogram

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cause for the seizures and possibly uncover an underlying structural or metabolic abnormality. The results were as follows:

Serum glucose (random) – 5,6mmol/l

Biochemical panel – Normal (all)

Serum VDRL – Negative

CSF – VDRL negative
Protein 0,12mg/l
No cells seen

Ct scan (high resolution) – Completely normal

So, I had found no evidence of cerebral syphylis, neurocysticercosis (which I had considered quite likely in view of his rural background) or metabolic disorder. We were left with a diagnosis of idiopathic epilepsy.

Intellectually he did not believe in ancestral curses but he could not dismiss his fear

I decided to attempt another front line ACD as a single agent – phenytoin (valproate was not available at our clinic). I followed the principles of drug substitution and did it slowly over a period of three months. The changeover did not go without some hiccups due to interactions between the two agents and a lot of serum level monitoring was done. S was finally stabilised on 400mg/day of phenytoin taken as a single dose at night. At this dose he had serum levels in the therapeutic range and initially appeared to have achieved better seizure control (two consecutive seizure free months).

However, this honeymoon period soon passed and his seizure frequency returned to its previous level. We tried to increase the dose of phenytoin to 500mg/day but he experienced severe ataxia and nausea at this dosage and had severely toxic serum levels.

By this stage S and I had developed a good relationship. I arranged to do a home visit and to visit his employer.

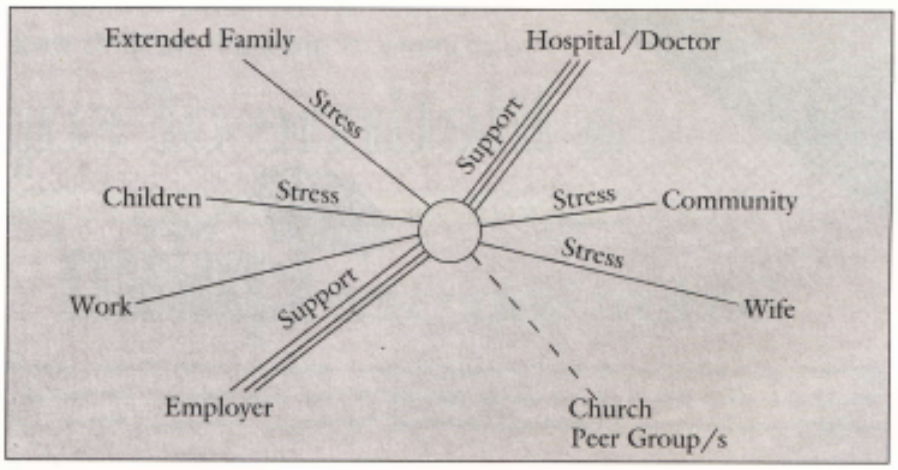
The home visit went without incident. The family lives in a three roomed brick house without electricity but with running cold water. There is a pit latrine outside for their use. Cooking is done using paraffin (a potential hazard for S) and the house was neat and tidy. They grew vegetables as well as flowering plants in a small, well tended garden.

His employer was most understanding and forthcoming and provided some useful information. He confirmed that he found S to be a valuable employee and claimed to find his seizures to be no more than an inconvenience. He seemed confident that he and his staff could cope with a seizure from a first aid point of view.

He informed me that S had become increasingly anxious about his condition in the last year or two. By what appears to have been co-incidence and bad luck, a number (at least four) of S's male relatives had died in the last two years from a variety of unrelated causes. At the funeral of the latest one (a cousin described as a "skollie" who had been stabbed to death), an elderly woman had informed S that he was under a family curse and that he would be the next to die!

I questioned S about this and he said that it caused him considerable anxiety. He claimed not to believe in traditional ancestral type curses at an intellectual level, but at another level he still did, to an extent. He had lost a number of relatives recently. He consulted several traditional healers in the past to deal with both his seizures and the curse but they had been of no benefit to him.

Eco Map



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We discussed this aspect of his situation over the course of several consultations and I gained the impression that S felt as though there was a brooding cloud hanging over him which he was able to dismiss at an intellectual level but which was ever present at a subconscious level.

I got to know S's wife at a later date when they consulted me together for advice about contraception. They did not feel that they could cope financially with more than the four children that they already had and wished for her to have a tubal ligation. They had run into problems with the extended family over this issue and were under some cultural and family pressure to have more children. After much debate and discussion they eventually felt able to exercise their autonomy and Mrs S underwent a laparoscopic tubal ligation.

Three Stage Diagnosis

1. Clinical

Poorly controlled epileptic
Compliant on drug therapy
No obvious precipitating cause
No obvious iatrogenic problems due to anti-convulsants
No structural neurological lesion found

2. Personal

Trying to cope in adverse circumstances with minimal support
Holding steady employment
Cast in a sick role at work and in the community
Isolated both at work and in his family
Afraid of implications of "the curse"

3. Contextual:

- in a dysfunctional marriage with a wife who offers no support but adds to his responsibilities
- has stable employment (against all odds)
- valued by employer
- ostracized socially due to - disease and its stigma - the "curse"
- almost no support forthcoming from either family or community (see eco map)
- still does not have full automomy in context of extended family

What next for S?

At a disease oriented level I suppose that the next step would be to try some ACD combination on S such as adding carbamazepine to the phenytoin. Other possible additions are sodium valproate and clonazepam or clobazam. (The latter is not on provincial code)

But what if we take a more patient-oriented approach? As can be seen rather dramatically in his three stage diagnosis and eco map, S is an isolated individual with very little in the way of support available to him. He is making an extremely valiant attempt to cope with his unfortunate circumstances. In the face of enormous odds, he is holding down a stable, reasonable job and has, so far, managed to keep his family together. The only avenues of support available to help him with his task are:
his employer
his medical attendant.

Metaphorically speaking, therefore, for S a seizure can be a method of temporarily escaping from the very onerous responsibilities of everyday life. A seizure at work does not involve a trip to the hospital, but it does allow a period of responsibility free rest. Reporting the seizure to the doctor at the next clinic visit will also elicit an interested and caring response.

I am not suggesting that S does not have genuine seizures, but I strongly suspect that his stress is a type of trigger factor - along the better understood lines of an alcoholic binge. It is just not as easy to spot and to quantify.

Over the course of several months, I explored this line of reasoning with S and he was prepared to admit that this was at least a possibility. We attempted to learn ways of dealing with stress and the family have been referred to FAMSA. We have changed his medication back to carbamazepine in view of its less toxic side effect profile. He is still having infrequent seizures at the rate of about one every six weeks. Despite this apparant lack of "organic" progress I am convinced that S is far more at ease with his situation in general.

Conclusion

I am thoroughly convinced that the secret of treating patients with seizures (or anything else) is to be patient centred and thus to attempt to understand the individual and his or her life circumstances. Failure to do this may leave many potential avenues of help unexplored. I hope that this example has illustrated the importance of constantly applying the basic principles of Family Medicine.

References

1. McWhinney I. The Principles of Family Medicine. In: A Textbook of Family Medicine. Oxford University Press 1989: 12-26.