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Chronic fatigue syndrome /myalgic encephalitis

The editorial in the May 2002 issue by Drs Stanley, Peters and Salmon¹ questions the validity of the report to the Chief Medical Officer stating that chronic fatigue syndrome/myalgic encephalopathy (CFS/ME) 'is indeed a chronic illness meriting significant NHS resources, including the unreserved attention of the medical profession.' They suggest that CFS/ME may be a 'social epidemic' where symptoms are generated by psychogenic mechanisms. They set high standards for discussions of these issues, advocating that information 'must be interpreted within a rigorous scientific framework such as that afforded by the methods of qualitative research.' Let us do just that. There have been repeated reports of objectively measurable physiological changes in CFS/ME,²⁻⁴ including:

1. immune (NK cell) dysfunction;
2. elevated levels of inflammatory cytokines;
3. elevated levels of neopterin;
4. elevated levels of oxidative damage;
5. orthostatic intolerance;
6. elevated levels of 37 kD RNase L;
7. energy metabolism/mitochondrial dysfunction; and,
8. neuroendocrine dysfunction.

In order to stay within their 'rigorous scientific framework' Drs Stanley, Peters and Salmon must either show that each of these studies from multiple research groups are invalid or that they are consistent with their interpretation. They have done neither.

Properties of 'medically unexplained' illnesses, including CFS/ME, may have already been explained.²⁻⁷

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Readers of your editorial of May 2002¹ may easily gain the impression that the medical profession's 'established scientific methods' have shown that CFS/ME is not a real illness and that people with CFS/ME are not really ill but are simply unhappy.

Such a perception of CFS/ME runs strongly counter to our experience at the registered charity, Westcare UK. Over the past 13 years we have been offering, with beneficial results,² professional help to well over 700 patients with CFS/ME. A significant part of our work consists in helping patients to identify and deal with psychological

and social factors that may have a bearing on their illness.³

We have no doubt at all that patients with CFS/ME are genuinely and seriously ill and that the severity, nature and course of their symptoms go far beyond the 'physiological manifestations of unhappiness'. There may be legitimate debate about how their illness is best named and defined, but any claim that the medical profession's 'established scientific methods' have shown that patients with CFS/ME are not really ill, goes far beyond the available evidence.

We see no good reason to believe that CFS/ME in general is caused primarily by social or psychological factors. The social factors which we see as most significant are very different from the ones mentioned in the editorial. Perhaps the most demoralising for patients is the culture of suspicion and disbelief that exists in the NHS and the Benefits Agency.

Current conceptual models for unexplained symptoms and syndromes all too often lead to the exaggeration or invention of possible roles for psychological or social factors. Too often it is wrongly assumed that if a syndrome has no *known* physical cause then there must be no *actual* physical cause and the cause must therefore be psychological or social.⁴ We urgently need better conceptual models which allow for the possibility of physical causes as yet undiscovered by modern science, and we need a changed medical culture which is more aware of the limits of its own expertise and is cautious about making inferences about the role of psychological and social factors unless the grounds for doing so are both positive and strong.⁵

At Westcare UK, we are grateful for the help that intelligent and self-aware

patients have given us towards a better understanding of their illness. We would like other health practitioners to be able to benefit from such help.

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In their editorial¹ (Journal, May 2002), Stanley *et al* argued that chronic fatigue should be categorised under 'persistent unexplained physical symptoms', and that these are often the result of the somatisation of 'unhappiness' and the misinterpretation of 'normal functioning'. However, their analysis contained some notable flaws.

Firstly, there is more to chronic fatigue syndrome (CFS) than 'tiredness and its synonyms' and to ignore symptoms, such as vertigo, nausea, and photophobia, both misrepresents and trivialises this illness.

Secondly, the authors alluded to widespread somatisation, despite the lack of evidence that this is a major problem in relation to CFS.² The suggestion that this is a homogeneous population of unhappy, prejudiced, attention-seekers is difficult to reconcile with evidence-based medicine, and the subtle accusations of mass exaggeration are stigmatising and unhelpful.

Thirdly, the authors posited that the recognition of CFS as a distinct syndrome 'runs counter to trends in recent research'. They supported this claim with two references: a viewpoint paper and an editorial. Do one speculative discussion paper and the sum-

mary of one study constitute a trend? I know of several well-designed studies which found strong evidence for the existence of CFS as a discrete entity.² Shouldn't one consider quality as well as quantity? Similarly, they proposed that the 'key influence on the perpetuation of unexplained symptoms appears to be the medical profession itself'. They again offered two references. One is a heavily criticised review; the other is an unpublished study that we cannot evaluate. Do these justify such a sweeping statement?

Finally, the authors suggested that the group advising the chief medical officer was forced to recognise CFS as an illness. They implied that there was 'pressure' from the patients, thus denying the input from researchers and clinicians of the stature of Professor Simon Wessely. If there was any 'pressure', was it not limited to the inclusion of an anecdote-based section on pacing?⁴ As for the claim that the group 'allowed consumerism in health care to define an illness', why would patients demand the recognition of ME, defined as an illness in 1956, or CFS, defined as a syndrome in 1988?

The authors emphasised the importance of the scientific method yet their analysis was marred by a lack of conceptual precision, exaggeration, generalisation and speculation. If we accept such subjective interpretations of the literature, can we really criticise patient groups who do the same?

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4. Eaton L. Chronic fatigue report delayed as row breaks out over content. *BMJ* 2002; **324**: 7.

Authors' response

Professor Pall challenges us with a list of physiological changes reported in CFS/ME. To quote from page 19 of the CMO's report¹ 'Research has demonstrated immune, endocrine, musculoskeletal and neurological abnormalities, which could be either part of the primary disease process or secondary consequences.' It is a naïve form of reductionism to make the assumption that a correlation of physiology with illness behaviour necessarily indicates that the former caused the latter. Indeed, were Professor Pall's view to be adopted, then many of the distressing phenomena with physiological correlates that doctors do not currently regard as diseases² would have to be so designated. There is, therefore, no need for us to question the validity of the physiological findings: if they are correlates or secondary consequences this is entirely consistent with the social origins of persistent unexplained physical symptoms (PUPS).

We commend Dr Sykes and his colleagues for helping many patients with CFS/ME by addressing 'psychological and social factors that may have a bearing on their illness'. In Dr Sykes opinion the 'most demoralising' of these factors is the 'culture of suspicion and disbelief that exists in the NHS and Benefits Agency'. Careful reading of our editorial will reveal that we do not advocate 'disbelief' by health professionals involved in the care of patients with PUPS, but constructive engagement; elsewhere,³ we cite difficulties in justifying their disability to others as a contributory factor in the anxiety and depression prevalent in patients with PUPS. Our editorial explicitly stated that patients with PUPS believe themselves to be ill and experience very significant disability. However, as Dr Sykes must realise, illness beliefs and behaviour, however convincing, do not amount to proof of a physical cause.

We do not altogether recognise our editorial from the points with which Dr Goudsmit takes issue. At no point did we describe the symptoms as 'normal functioning' neither did we 'trivialise' the suffering of patients with PUPS. We have, indeed, reported that they are even more disabled than those with

other chronic diseases, including rheumatoid arthritis.³ Dr Goudsmit has entirely missed the point about other persistent physical symptoms which accompany fatigue and its synonyms; far from validating CFS, because they are also found in patients without fatigue, they undermine the authenticity of CFS as a discrete syndrome. Careful reading of the editorial will show that Dr Goudsmit is mistaken in her belief that we subscribe to the theory that somatisation of mental illness is the cause of PUPS. Nowhere did we refer to a 'homogeneous population of unhappy, prejudiced attention-seekers' or accuse sufferers of 'mass exaggeration'. Her criticism of our references is similarly inaccurate: of the two references supporting our view of trends in recent research on PUPS one is a review not a 'viewpoint paper'; and it is incorrect to describe as 'unpublished' our paper supporting the claim that the medical profession is a key influence on perpetuation of unexplained symptoms. In fact, it was cited as 'in press' and the journal name provided; we are now able to provide her with full details of publication.³ For a better understanding of why the workings of the CMO's group were controversial, we refer Dr Goudsmit to the article by Michael Fitzpatrick⁴ in the same edition of the *BJGP* as our editorial. Her final, sweeping and emotive criticism of us might bear scrutiny if, in her letter, Dr Goudsmit had demonstrated that she was prepared and able accurately to read and interpret a scientific article.

In a previously published letter,⁵ Chris Clark of Action for ME describes as 'quite ludicrous' our view that for patients with PUPS there are gains involved in adopting victim status. He appears to be unaware of half a century of related scholarship and research; as a starting point, we refer him to Parson's seminal work⁶ on the sick role. He might also note the reference by Dr Sykes to the importance of these patients' relationship with the Benefits Agency.

It should not be forgotten that adherents to a reductionist scientific approach, lobbyists for a variety of therapies, and ME pressure groups have a vested interest in perpetuating all, or a sub-set of, PUPS as disease

rather than a socially determined phenomenon. Readers of the *BJGP* may draw their own conclusions about the difficulty of rational debate on this subject from the vehemence with which our views have been dismissed, from the eagerness to label us as 'unscientific' and from the ways in which our argument is distorted into one that can be attacked on moral rather than scientific grounds, as being malign or unfair.

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GPs and child protection

Another cry that GPs must do better, this time about child protection:¹ yet no specific detail on how we are to do it, just a general sense of being berated for poor performance.

I suspect that for most GPs, child protection work is done in addition to an already overfull day's work. I work in a suburban practice and probably have far less child protection work than my city centre colleagues. I send a written report to child protection case conferences, (invariably compiled after 6pm). I no longer attend these meetings, which usually last longer than two hours. Should I choose to attend, I could arrange locum cover, (if I can get a locum at the usually short notice). The fee I receive for attending the meeting will not be enough to pay

for the locum I've employed. Alternatively, I can lengthen my working day by the length of the conference plus travelling time. The first option allows me to pay for the privilege of my involvement in child protection work. The second option allows my children to pay because yet another evening of family time is lost. Why are GPs routinely expected to protect other peoples' children at the expense of their own?

My last two involvements in child protection work have felt extremely futile. It took three months of repeated badgering by our community midwife and myself to persuade a local social services child protection team to engage with a pregnant woman who already had children in care in another part of the country. She had high needs and presented high risks: we were told that the delay was through failure of a distant social services department to 'hand over' the case. More recently, my report to a case conference was misrepresented at the conference, watering down my concerns for the child. Such attempts to be involved can feel very much like banging my head against the proverbial brick wall.

It is not good enough to say 'Health professionals are expected to respect the paramount principle that places the welfare of children above all other consideration.' The other calls on my time and other personal resources do not simply disappear in the face of this instruction: each group believes that their cause has more priority than the next. GPs have to be experts in juggling demand if they are to have any hope of avoiding burnout.

Like my colleagues, I will continue to do what I can, but it would help if high profile RCGP figures did not stoke up unrealistic expectations. Is it too much to hope that child protection procedures may one day reflect a recognition of the other demands on GPs' time? Even better, might it one day be possible for a GP to make a full contribution to child protection work within a normal working day, rather than by extending that day?

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Reference

1. Carter YH, Bannon MJ. Viewpoint 2 — GPs and child protection: time to grasp the nettle. *Br J Gen Pract* 2002; **52**: 514.

New contract and career development

I agree with Roger Jones,¹ who, writing about the new contract, would have liked to have seen a much bolder attempt to endorse the 'mixed portfolio' approach to general practice in which patient care is combined with other non-clinical activities, notably research and teaching. He also intends to introduce a 'wedge-shaped' commitment with substantial work in the early years, tapering to a considerably reduced commitment for more senior doctors (I'd add also the growing numbers of female GPs women who need part-time or different styles of work). Really, this would be a chance to reinvent general practice as an attractive career with a progressive career structure.

At the WONCA Congress in London, I organised a Symposium² entitled 'Towards a flexible career development for GPs' along with colleagues Christos Lionis, Erwin Rebhandl, Sorayya Mahmood, and Geoff Martin.

Career development and prevention of burn-out in general practice or family medicine are dependent on a variety of factors, but the two issues which are pre-eminent are:

1. *Professional satisfaction in the primary role.* This is largely determined by:
 - recognised training and qualification, which largely excludes poorly trained and/or incompetent practitioners;
 - recognition of general practice/family medicine as a specialist discipline; and
 - availability of professional peer-driven continuing education;
 - adequate remuneration and lifestyle, at least comparable to specialist colleagues.
2. *Availability of alternative career options within the discipline.* There are unlikely to be many alternative career options at all for GPs/family

physicians until the first three of the above criteria have been met in the following way:

- recognised training and qualification generates an academic body of general practice/family medicine;
- the academic body must then attain recognition and parity with other disciplines, for example in the appointment of full professors, etc; and
- only then will career options become available.

The unique contribution that the primary care physician can make to other multi-disciplinary settings will not be recognised until the discipline itself is recognised and achieves appropriate status.

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Reference

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RCGP membership, icing on the cake?

Thornett and colleagues assess whether membership of the RCGP makes GPs better at recognising depression.¹ Apparently it does not. Perhaps a more worthwhile study would have been to determine whether a six-month attachment in psychiatry makes GPs better able to diagnose and treat depression and other mental illnesses in their patients. Being able to differentiate depression from the glut of dysphoria in society would also be a real advantage. Can we now expect a series of papers testing whether membership of the RCGP makes doctors better at diagnosing heart failure, pancreatitis or the common cold or even at making coffee? Yes, membership is an achievement, but it would be naïve to believe that in itself it makes a more rounded and competent doctor. Vocational training is now so comprehensive that college membership could be regarded as the icing on the

cake.

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Reference

1. Thornett AM, Pickering RM, Willis T, Thompson C. Membership of the Royal College of General Practitioners and recognition of depression in primary care. *Br J Gen Pract* 2002; **52**: 563-566.

Frequent consulters

The need for more rigorous definitions of frequent consulting, including how to address age and sex issues is well established,¹ as is the contribution of both age and sex variables to groups of frequent consulters.² Howe and colleagues present a pragmatic study of defining frequent consulting in general practice.³ Given the reaction that many GPs have towards their frequent consulters, this study may have GPs running to their computer's search function to define their frequently consulting cohort of patients. However, I have concerns about the contribution that this paper makes to our understanding of researching frequent consulters, and of the implications of the findings.

One of the difficulties in defining frequent consulting is the use of short-term data. Many studies — this one included — use data only over a one-year period. Longitudinal studies of frequent consulting show a clear regression to the mean in subsequent years with, on average, only about one-third of frequent consulters continuing to be frequent consulters in the following year.⁴⁻⁸ Hence, once practices or researchers have identified a retrospective cohort of patients based on one year's data, over two-thirds of the cohort will already be resorting to more usual patterns of consulting.

Perhaps most importantly we should question the rationale for wanting to identify patients whose attendance patterns are unusual (whether or not this includes a correction for age and sex). The philosophy driving this seems to be a desire to intervene to address 'deviant' behaviour. This is despite no methodologically sound studies demonstrating either the 'inap-

propriateness' of frequent consulting, or any significant benefits of interventions aimed at frequent consulters. Furthermore, the influence of individual doctors over unusual patterns of attendance has been established.⁹ Intervention strategies for problematic frequent consulting, however defined, may therefore be best targeted at health professionals and the organisation of service delivery in primary care, rather than frequent consulters themselves.¹

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Reference

1. Neal R, Dowell A, Heywood P, Morley S. Frequent attenders — who needs treatment? *Br J Gen Pract* 1996; **46**: 131-132.
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5. Carney TA, Guy S, Jeffrey G. Frequent attenders in general practice: a retrospective 20-year follow-up study. *Br J Gen Pract* 2001; **51**: 567-569.
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9. Neal RD, Morley S, Heywood PL. Frequent attenders' consulting patterns with general practitioners. *Br J Gen Pract* 2000; **50**: 972-976.

Poor performance?

David Mant's article¹ starts with a restating of Julian Tudor Hart's 'inverse care law', and then argues that the way forward for general practice is the recognition and management of poor performance, with 'the creation of PCTs providing ... an unprecedented

opportunity ... to deal more effectively and fluently with the issue of poor quality care'. But there are at least two problems that will need addressing before any progress of the sort he intends can be made. First, the definition of poor performance. Secondly, Mant makes no reference to the problems that are created for some GPs by the very nature of the people they are trying to care for, and the inevitable, large, and negative contribution that these people make to the 'inverse care' that they receive.

I work as a single-handed GP in an inner-city practice. Despite the high turnover of our list, and the fact that a high proportion of our patients live in bedsits, there are now no children on our practice list who are eligible for vaccinations who have not received them, except those whose parents have refused. Similarly, there are now no eligible women on our surgery list who have not either had an up-to-date smear, or signed a disclaimer. Yet, despite the massive effort involved in these two areas, we only achieve an 83% uptake of cervical smears, and we have recently, for the first time, failed to achieve the 90% target for MMR. This is, of course, despite maximal effort in patient education etc., and is completely beyond our control. Judged by government targets, we are failing, but doing any better is impossible for us. If David Mant worked for Exeter PCT, I wonder if he would describe my surgery or me as a 'poor performer'? This problem is set to get worse if the proposed new contract comes into effect, because performance in many areas of care will then be judged on a plethora of numerical 'quality markers'. Even if the new contract takes into account 'refuseniks' in these quality targets, there will still be the problem of what to do about the patient who says 'Yes doctor, I know I need my cholesterol/blood pressure/asthma/diabetes, etc. checked', but who then doesn't bother to turn up.

The sad fact is that, where GPs try to care for 'more difficult patients', where hospitals take on 'more challenging surgery', where police try law enforcement in 'more lawless areas', where teachers try to teach 'more difficult children', in fact, wherever anyone tries to do anything that is harder to do

in a way which cannot be measured, that person appears doomed to being marked down by those who judge 'performance'. This could perhaps be called 'Eggleton's Law of Inverse Credit'. It is time we faced up to this, and gave those who struggle against all the odds some credit, rather than criticism, for whatever they achieve in the face of adversity. I, for one, will have no respect for, or confidence in, 'performance evaluation' for GPs until I see robust (and local medical committee-backed) methodology in place, to allow for the effect of differing patient populations.

And one final thought. What, I wonder, in this minefield of performance comparisons, does Professor Mant make of the recent Audit Commission finding, that £63 per patient per year is allocated for primary healthcare in Oxfordshire, as opposed to £33 in Tyne and Wear?

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Reference

1. Mant D. A case of mural dyslexia. *Br J Gen Pract* 2002; **52**: 579-583.

The power of statistics

Freemantle *et al*¹ have made a strong objection to the commentary by Matthew Lockyer which was published with their paper on educational outreach by community pharmacists.² It seems to me, however, that the commentary was reasonable and that its publication was appropriate.

Lockyer commented on the small degree of change that was detected. There was a 5.2% change in prescribing behaviour in the intervention group. To quote from Freemantle *et al*,² 'the minimum change in treatment that was considered to be significant ... was for two patients [out of 25] per practice to move from outside to within the guideline recommendations for each guideline'. Two patients in 25 as a percentage is 8%, so by the authors' own criterion this study has failed to show a clinically significant change in prescribing behaviour.

Much of the overall effect is due to the specific guideline for aspirin (in angina), which, at 7%, shows a signifi-

cantly greater effect than any of the other three guidelines. There is, however, a source of bias in the way adherence to this guideline was measured post intervention. Freemantle *et al*² say 'The outreach visits emphasised the importance of practitioners prescribing at least one dose of aspirin and recording in the notes if aspirin was being purchased over the counter.' Instead of the post intervention measurement picking up only patients who have been prescribed aspirin according to the guidelines, it would also have picked up patients who were taking aspirin before intervention but who could not be detected then because of lack of recording. To avoid this, practitioners should have been told *not* to prescribe for or make entries in the notes of patients who are already buying aspirin over the counter (until the second measurement had taken place).

Lockyer also commented on the wide confidence intervals in the study, which Freemantle *et al*.¹ explain as owing to the effect of clustering at the practice level. More precision (smaller confidence intervals) could have been achieved by including more practices in the study with fewer patients sampled in each practice. With a clustered study design it is not necessary to make very precise estimates of proportions within each cluster. Of course, there may have been difficulties in recruiting practices, but a final total of 69 practices completing the study seems small when data was collected on over 10 000 patients!

However, although some confidence intervals are wide, I don't think lack of precision or statistical power is a problem with this study. On the contrary, some small effect sizes are statistically significant, suggesting that the study may be statistically powerful, with a risk of a type I statistical error (rejecting the null hypothesis when it is true).

During a secondary analysis of their data, Freemantle *et al*.^{1,2} found a statistically significant interaction effect between surgery size and outcome. The effect of intervention on prescribing was concentrated in small (one or two-member) practices, with a 13.5% change in prescribing behaviour and essentially no effect (1.4% change) in larger practices. They do not explore

the implications of this for the general population. Given that small practices had a mean of 1.4 partners, large practices had a mean of 4.4 partners and the overall mean was 2.75 partners, it would seem that in this sample 45% of practices are large. Assuming that the list size for each practice is proportional to the number of partners, the proportion of patients who are registered with large practices is 72%. Since small practices in this sample are over-represented because of the sampling procedure, the proportion of patients registered with large practices in the general population is likely to be greater than this.

Targeting small practices would mean making visits to half the practices in an area but would be of no benefit to three-quarters of the population and only of marginal benefit to the remaining quarter.

In their discussion, Freemantle *et al*² have focused on statistically significant results but not the clinical implications of their findings. They have not shown any substantial benefit from community outreach by pharmacists for the majority of patients. However, I welcome this paper's publication. The publication of negative findings in studies of good statistical power is necessary to prevent publication bias in the medical literature.

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Correction

In the March 2002 issue of the *BJGP*, reference 9 in the article by Freemantle *et al*,² was wrongly stated to have been published by the Cancer Research Campaign. It was in fact published by CRC Press of Boca Raton, Florida. The correct reference is therefore: Collett D. *Modelling Binary Data*. London: Chapman & Hall/Boca Raton, Florida: CRC Press LLC, 1991. We apologise for any confusion this may have caused

Reference

1. Freemantle N, Nazareth I, Wood J *et al*. Commentary on the EBOR trial report. [Letter.] *Br J Gen Pract* 2002; **52**: 588.
2. Freemantle N, Nazareth I, Eccles M *et al*.

A randomised trial of the effect of educational outreach by community pharmacists on prescribing in UK General Practice. *Br J Gen Pract* 2002; **52**: 290-295.

General practice Down Under

After reading your two recent articles about general practice in Australia,^{1,2} I have been inspired to reply. As an Australian general practice registrar, I worked in general practice in the United Kingdom for about 12 months. I thought the UK general practice system was better than the Australian for me as a doctor. Interestingly, my fellow (non-medical) compatriots found the UK system less user-friendly than home. For me the benefits lay in the largely unspoken concept that the role of the doctor and health centre in the UK is to keep patients healthy and out of the surgery. This encourages health promotion and education. In Australia, it feels more like I am dispensing healthcare to the sick and worried, as if selling bread from the corner shop. There is little concept of keeping people healthy. Admittedly, the Federal Government is trying to change this to some extent by linking cumulative evidence of preventive medical practice to incentive payments. However, in reality this involves a lot of paperwork for little financial gain.

I also worked in the UK hospital system for 18 months but I won't go into that!

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Reference

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