Frustrating survey of chronic fatigue

Last week, three U K Royal Colleges of medicine produced a report entitled Chronic Fatigue Syndrome (available from the Royal College of Physicians). The condition shall now be called chronic fatigue syndrome (C F S) and not myalgic encephalomyelitis (M E), the report decrees. M E is an unsuitable name because it implies a pathological condition that is not there, it implies a single disease entity, and it ignores the psychological dimension. The Royal Colleges set to work after a request from the government’s C hief Medical Officer.

The committee’s estimate of the prevalence of C F S sparked a furious onslaught from the M E/C F S charities. The expert committee took U S data of 0·1-0·9% and U K data up to 2·6% to arrive at a figure of 1·2%, equivalent to a maximum of about 40 cases on the average general practitioner’s list or to half to one million cases in the U K. The M E/C F S Charities Alliance gives a figure of 150 000 cases (a doubling of a general practice survey that showed 50 000-75 000 cases), while the Persistent Virus Disease Research Foundation suggests 100 000. All would agree on a large measure of imprecision for such estimates, but the official report is about an order of magnitude higher in its total. The D epartment of H ealth would commit itself only to “several thousands”, and would not be drawn to define “several” or comment on the report’s high estimate.

The expert committee dismisses, for lack of evidence, a major role for a viral cause of C F S or for structural or functional abnormalities in muscle or brain. For instance, one study showed brainstem hypoperfusion in patients with C F S compared with controls, an important finding because the brainstem contains systems for activation and inhibition of sleep, consciousness, arousal, and movement. But the study’s lead author, D urval C costa from U niversity C ollege L ondon, told The L ancet that the committee was too quick to reject his work because others have “technical difficulty” with whole-volume single-photon emission tomography, the technique he uses.

The report points out that in studies of psychiatric disorder in C F S, about half the patients fulfilled criteria for affective disorder and a further quarter had other psychiatric illness, mainly anxiety and somatisation disorders. T his is where the charities cry “foul”. T he sixteen-strong committee was top-heavy with psychiatric experts, so the emphasis on psychological causes and management (introduction of graded exercise and cognitive behaviour therapy) is no surprise. C harles Shepherd, medical director for the M E Association, told us that “the committee was rigged, with dissenting voices excluded”. He feels that a 1984 report published by the charity Westcare, which prompted the latest report, was “too physically oriented” for some people and it called for the government to fund research. Certainly, the expert committee describes no attempt to collect external opinions, and the report is little more than a literature survey.

The latest report has few implications for funding, even though it takes a broad sweep at the burden of the condition for patients, their families, and society, without any quantification. T he committee’s terms of reference included a brief to look at service provision; indeed, one member was a commissioner who buys health-care services, and a whole appendix is a special summary for commissioners. After emphasising management within primary care, the report then says that the secondary sector is “often inadequate”, suggesting the low-cost option of setting up multidisciplinary teams.

Psychiatry has won the day for now. A decade hence, when an organic cause for at least some cases of C F S may have emerged, it would be tempting to ask the committee to reconvene. W e believe that the report was haphazardly set-up, biased, and inconclusive, and is of little help to patients or their physicians. O r as the D epartment of H ealth weakly put it, the report will “provide a further contribution to the ongoing debate”. Incidentally, the D epartment still talks about C F S/M E.

T he L ancet