AKUREYRI DISEASE (MYALGIC ENCEPHALOMYELITIS), FORTY YEARS LATER

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SIR,- In 1948 an epidemic resembling myalgic encephalomyelitis (ME) struck the north of Iceland, and in Akureyri alone 476 people fell ill. In May, 1988, we reviewed 8 women and 2 men aged 45-84 (9 affected in 1948 and the other in 1955) to determine the very long-term sequelae, if any. The Lancet carried the six-year follow-up in 1956. (2) In 1947, the year before their chronic illness, 3 of the 10 patients had reported a similar episode lasting about a fortnight, with burning limb pain, prostration, and muscular weakness. 1 of these patients was the gym teacher at the Akureyri school where so many of the students were to fall ill. Her husband and 2 of her children also fell ill in 1948. The husband of another had had poliomyelitis in 1945, and Dr Julius Sigurjonsson recalls that ME-like features occurred in the Icelandic poliomyelitis epidemics of 1945-47.

Relapse is a feature of almost all published series on epidemic ME but after the initial few years none of the 10 patients mentioned recurrences. It is possible that claims of recurrences noted by both patients and physicians may simply indicate that the patient has gone beyond the physical limitations imposed by this chronic illness. On clinical grounds only 2 patients indicated a total physical and intellectual recovery--namely, the teacher mentioned above and the youngest patient. At interview no patient showed obvious hysteria or neuroticism and they seemed well adjusted and successful. There was no suggestion of depression although 2 patients mentioned severe reactive depression earlier in the disease. Marital and other social relationships had not been harmed. 2 women who had been severely paralysed at first were admitted for long-term care in hospitals outside Iceland. The paralysis lasted for almost 2 years but one woman's father and the other's fiancé accompanied them and provided considerable emotional support during this uncertain and stressful period. Both recovered, though muscular weakness persists. When problems arose they stemmed from the refusal by doctors to believe that the patient was really ill, hysterical paralysis being the preferred diagnosis.

1 patient, possibly the first to fall ill with Akureyri disease, recalls: "I was in severe pain, I had no fever, but I could not urinate and I was unable to move either of my legs". But when the doctor came he would not believe that there was anything wrong. Initially, patients were often shunned by others (including 1192 nurses and friends) because of the fear of catching a terrifying infectious disease. Only 1 adult (the gymnastics teacher) and the 5-year-old child have returned to active sport. The other 8 patients varied between

permanent paralysis and minor physical disabilities. 1 patient who fell ill at the age of 18 and had 2 years of severe muscular weakness later became a major public figure in Iceland. He recalls that the disease changed his life: "I have never since dared to attempt my physical limits for fear that they would fail me. After I was strong enough to return to school, even at dances I would go home early, and in a way this gave me an advantage over others since I knew I could count on my mental abilities as long as I did not push my physical abilities". He had not met anyone affected by Akureyri disease who had recovered as well as he had- but in 1988 this man still had a positive Rhomberg test and abnormal visual saccades and he cannot tackle a long letter without severe deterioration in his writing. Perhaps this claim to total recovery is related to the fact that some doctors in Iceland to this day think that the disease was simply hysteria. It would be important for someone in a major government post to distance himself from such a label.

This denial of ME-like illness is not unique to Iceland. Dr A. M. Ramsay told a meeting of the Epidemic Myalgic Encephalomyelitis Study Group in London (May, 1988) that nurses affected in the 1955 Royal Free Hospital epidemic had been so ridiculed by some physicians that they have refused to talk about the long-term consequences of the disease. Such denial is the opposite of what one would anticipate from a patient with hysteria. Since publication of Behan and colleagues' paper showing that ME (postviral fatigue syndrome) is primarily a motoneuron disease associated with a disordered immune system (3) the hysteria theory has been taken less seriously. Virological evidence is emerging too, and the recovery of virus from the stools up to 3 years after the initial infection (4), may be significant to the brief 1947 illnesses in 3 of our patients. Subjectively only 13% and objectively only 30% of 39 Akureyri patients examined had completely recovered after 6 years. The general fatigue, muscle pain, tenderness, weakness, and neurological complaints described then resemble those we noted 40 years after. The lack of obvious psychological illness may be related to the support these patients have had from family, friends, and the community and the state. Today there is an acceptance of these individuals' physical limitations, an acceptance that may not have been forthcoming in the early years.

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