

BEYOND THE MONTHLY SEIZURE COUNT

The Social Causes of Inequality in Epilepsy and Developing a Rehabilitation Strategy: A U.K.-Based Analysis. Ridsdale L. *Epilepsia* 2009;50(10):2175–2179. A rehabilitation approach has been adopted for many long-term neurologic conditions, but not for epilepsy. The disabilities associated with epilepsy are cognitive, psychological, and social, which are not as readily identified by medical doctors as are physical disabilities. A rehabilitation approach moves the emphasis from a medically driven process to a focus on the personal, social, and physical context of long-term illness. It is suggested that a missed opportunity for education and support for self-management occurs after diagnosis. This results in disadvantage to those whose educational level and knowledge of epilepsy are low. People who do not achieve epilepsy control may then experience higher levels of psychological distress, and a negative cycle of loss of self-efficacy, poor epilepsy control, social disadvantage, and disability. Rehabilitation services have benefited communities surrounding centers of excellence. Not so in epilepsy. Despite centers of excellence, areas with deprivation have higher than national average levels of patients reporting a seizure in the prior year, and higher emergency hospital admissions. Specialists working in partnership with general practitioners (GPs) and practice nurses can do more to increase participation and reduce distress for people with epilepsy. When available, GPs and nurses with special interest in epilepsy promote integrated services. Primary–secondary networks are likely to be more effective in preventing downward drift. This requires evaluation.

COMMENTARY

The focus of most research and educational programs relating to the care of patients with epilepsy is a reduction in the frequency of seizures. Identifying seizure types, choosing an appropriate drug, measuring serum drug levels, and monitoring dose-limiting side effects are chief goals of most treating physicians. Yet, to some extent, the frequency of seizures is only a marker for and a predictor of the major preoccupations of most patients with seizures, which concern the daily management of their condition. For the individual with epilepsy, discussions of its immediate and long-term effects on self-esteem, cognition, social function, mood, and employment often dominate most treatment visits if permitted by the physician. The paper by Ridsdale is a reminder of this fact, emphasizing the additional burden sustained by those patients from socially deprived communities and backgrounds.

“Rehabilitation” may seem like an unusual word to apply to the care of those with epilepsy. However, Ridsdale explains that the National Health Service of the United Kingdom defines such rehabilitation as programs that: “increase a patient’s capacity to participate in the community, and reduce distress and inequality throughout life,”—factors central to the concerns of patients and to the responsibilities of health care providers. The specific recommendations that Ridsdale describes are derived from the National Institute for Clinical Excellence (NICE)

Guidelines and are applied to the U.K.’s National Health Service. Much of the impact of epilepsy is the same everywhere, but the response to it will be shaped or limited by local resources.

The medical literature on the complications of epilepsy continues to grow. The risk of cognitive deficits in children is increasingly recognized. Mood disorders, underemployment, reduced marriage and fertility rates, complications of child bearing, and social stigmatization have been well documented. Similarly, the list of the short- and long-term effects of antiepileptic drug use lengthens. So far, however, discussions about the appropriate practical responses to these complications have lagged. This paper describes some of the reasons for the delay in addressing these common obstacles to comprehensive epilepsy care and proposes some solutions.

The care of individuals with epilepsy begins with an accurate diagnosis made by a knowledgeable health care professional. In some well-funded health care systems, the clinician may be a neurologist or even an epileptologist, but in other circumstances, she or he will be a primary care physician or a trained clinical health care worker. The physician may immediately jump to the next step of choosing and starting medication, while the patient’s first response to the diagnosis is the need for information. A survey of patients seen in one tertiary care practice several years ago revealed that the greatest unfulfilled need was that for more information about epilepsy (1). A study by Ridsdale et al., in 2000, revealed that the knowledge gap regarding the health and psychosocial complications of epilepsy was greatest in patients with less education and that the gap

could be eliminated by a program of instruction by a specialist nurse (2).

The initial emotional response of patients to a new diagnosis of epilepsy may provide clues to the best management approach. Experienced clinicians are well aware of the difficulty in establishing effective, well-tolerated medical treatment in patients who deny their illness, are phobic or suspicious about medication, or are angry about their diagnosis. Other patients sift the Internet for dietary or other nontraditional treatments or cures for seizures, often with proportionate skepticism about the physician's own recommendations. How can physicians satisfy these complex, wide-ranging needs within the construct of most brief encounters with patients? Practically speaking, it is not possible. Thus, Ridsdale and others suggest the answer: move to a team approach to care. Following the physician's diagnosis and recommendations they suggest a needs assessment by nurse specialists who, in turn, have access to help from social workers, psychologists, occupational therapists, and even employment officers and learning disability teams.

The argument for the need for a team approach with wide-ranging support and expertise is made fairly easily, but supplying such resources will always be large undertaking. First, many if not most physicians receive little training and have scant knowledge about heading multifaceted therapeutic teams. Undoubtedly, some epilepsy care centers already have a comprehensive approach to the care of patients with epilepsy, but moving toward this type of a model in routine epilepsy care may demand a culture change, in other settings. Second, the diverse support appropriate for this patient group is generally found only in large population settings. Third, even where such team members exist, funds within the medical care system for their use may not exist. Even the team leader, who is usually the physician, would remain unreimbursed for this role in many health care systems, including that of the United States.

Moving toward rehabilitation models of epilepsy care would require different strategies in various health care systems. Many other chronic disorders could be or already are suitably addressed by a comprehensive therapeutic approach. Effective models suitable for epilepsy care already exist, such as those

established for asthma and diabetes. Such programs are usually staffed by specialist nurses, who successfully teach self-care to children with proven reduction in medical crises and emergency room visits (3). Medical students and residents would need expanded training in and exposure to the role of health team leader. Patient-led advocacy groups, such as the Epilepsy Foundation, though not available everywhere, can provide many social and psychological supports, generally without cost to the individual. Helping to expand epilepsy support groups, or establishing them where they do not exist, has and can be done by professional groups and individuals.

Ridsdale points to a recent provision by the U.K.'s National Health Service of extra income for general practitioners for epilepsy care. This policy recognizes the special kind of medical supervision, organization, and clinician availability required in managing this chronic, often relapsing, condition. The approach might serve as a model for certain fee-for-service reimbursement health care plans in other settings for coverage of such ongoing care.

As Ridsdale notes, routine epilepsy rehabilitation is an emerging topic—the pursuit of which may present opportunities for research involving outcome studies, international comparisons, and cost-effectiveness. Most importantly, it offers the prospect of more fulfilling, happier lives for people with epilepsy.

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References

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