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Short survey

Medical management: From colony to community

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ABSTRACT

In this article the development from the colonies founded in the 19th century to the current situation is discussed. Future development is not to simply follow the slogan 'to the community' translated as 'epilepsy must be treated in general hospitals' but to preserve epileptology as specialized care with 'centres of excellence' orchestrated by coupling epilepsy centres with academical neurology.

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1. Introduction

Epilepsy care and cure have shown a substantial development over the past 60 years and this may be summarized by the title of this contribution: 'from colony to community'. When evaluating this development it is imperative to distinguish care and cure: care for those with chronic refractory epilepsy and cure for those patients that benefit from treatment and generally will only have epileptic seizures during a part of their life. The care for patients with chronic epilepsy is often complicated by learning disability. A separate group are those patients with difficult-to-treat epilepsies but who can benefit from available invasive treatment techniques such as epilepsy surgery or deep brain stimulation. When assessing developments over time it is also necessary to make a distinction between care and cure for children and adults. This all implies that it is unwise to speak in too general terms such as 'patients with epilepsy'. The situation is a far more complex one than that phrase implies.

2. The beginning: the time of the colonies

Epilepsy centres started their lives as 'colonies': large facilities, often outside the community in rural areas. Most of the epilepsy centres were founded in the late 19th century, often started by a few people and driven by Christian ideals of providing care and offering dignity. The history of these centres is parallel to that of the asylum movement, which originated at the same time for those with incurable mental illness.¹ Like the asylums of the late

Victorian era, the epilepsy colonies served as isolated communities where the afflicted were protected from stigmatising public view. It is important to realize that in the periods of foundation of the colonies no other treatments for epilepsy than bromide were available. Labour and fresh air were considered important treatments.

Four examples to illustrate the origins and developments of such centres:

- Anstalt Bethel, Bielfeld, Germany was founded in 1867 by pious merchants and salesmen. It is a non-governmental foundation with a Christian background. Originally long-term residential care was not an aim. Pedagogues had a dominant position in the centre and the first head was a teacher. In later years when it was discovered that few patients could be discharged and return to home, the concept of 'colony' was developed. Consequently not only people with epilepsy but also others, such as homeless, elderly and psychiatric patients were housed there. This is still the structure of the organization, with 7000 places and 11,000 staff members. Within this complex organization, Mara, an epilepsy hospital, was inaugurated in 1933 when facilities for treatment expanded. Nowadays the philosophy is one of comprehensive care, with an epilepsy clinic of about 100 beds, a unit for surgery (14 beds), vocational training, out-patient counseling (4000 visits annually), residential units (for 500 persons), sheltered workshops and a society for research. The epilepsy centre constitutes about 25% of the total centre.
- The Chalfont centre for Epilepsy also has an interesting background. The National Hospital for the Paralyzed and Epileptic was founded at Queen Square, London, in 1857. The Hospital has since been renamed The National Hospital for Neurology and Neurosurgery, which included famous pioneers of neurology and epileptology such as Gowers and Jackson. The National Society for

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the Employments of Epileptics, a charity organization, purchased a farm in Chalfont, Buckinghamshire in 1894. The name of the society was changed to the National Society for Epilepsy (NSE) in 1907. The NSE has provided residential care and public education from that time at the Chalfont site. In 1983, a unique tripartite arrangement was established between charity (NSE), university (Institute of Neurology of University College London) and hospital (The National Hospital for Neurology and Neurosurgery). This developed through continuous cooperation (for example by joint appointments) into a comprehensive spectrum of clinical care and research at the Chalfont and Queen Square sites.

- The Swiss Epilepsy Centre was founded in 1886 by a private association with Christian motives. They founded a place of refuge and healing for 'epileptics'. Until the 1950s the centre functioned as an asylum run on Christian principles. In the 1960s the institute underwent a phase of modernisation and physiotherapy, vocational training, psychology, etc. were introduced. The basic approach is now one of interdisciplinary collaboration. It has a hospital unit with 44 beds and a residential unit with 177 beds. There is an expanding cooperation with the University Hospital in Zurich.
- The Dutch epilepsy centre, Kempenhaeghe, was founded in 1919 by the Brothers of the Holy Joseph and was originally intended for nursing male epileptics. A monastery was built for this purpose, called Providentia. In 1953, the medical director of Providentia and the Dean of the village Heeze decided to build a parallel institution for female epileptics. This was run by the Congregation of Franciscan Nuns. After merging of the initiatives in 1971 a new foundation, 'Kempenhaeghe', became the legal body that administers the epilepsy centre at both locations. Currently the centre has out-patient facilities (about 15,000 visits annually), about 80 hospital beds, and a residential area with about 300 beds. There is also a large school. There is a close collaboration with the Maastricht University Medical Centre.

3. Development over time

Over the many decades that the epilepsy centres have existed, their role, position and services have changed considerably. However, the large epilepsy centres still show some similarities. They offer both ambulatory and inpatient care; they have assessment units (short stay hospital facilities), as well as a large number of beds (most centres have several hundreds) for residents with refractory epilepsy (long stay, residential care). The centres consider themselves as 'Centres of Excellence' or 'Centres of Competence' offering state-of-the-art multidisciplinary care. Some of these centres base this position on the facilities they offer, others also on a research portfolio that is coupled to patient care.

Since 2001 a European Association of Epilepsy Centres exists of which the founding members were: Epilepsiezentrum Bethel in Bielefeld, Germany; Kolonien Filadelfia, Dianalund in Denmark; Meer & Bosch, Heemstede, the Netherlands; Epilepsiecentrum Kempenhaeghe, Heeze, The Netherlands; Diakonie Kork Epilepsiezentrum, Kork, Germany; National Society for Epilepsy at the Chalfont centre, London, England; Spesialsykehuset for epilepsi, Sandvika, Norway; Etablissement Medical de la Teppe, Tain L'Hermitage, France; Schweizerisches EpilepsieZentrum, Zurich, Switzerland.²

It is difficult to provide a similar list for other areas in the world. Epilepsy centres, as defined above, are typically European institutions. Elsewhere in the world care is provided by neurological departments at general hospitals. Sometime 'an epilepsy centre' or 'epilepsy unit' is a separate unit within a general or university hospital, with a few beds (<10), especially for EEG monitoring. People with permanent problems outside the direct field of cure generally reside in homes for people with mental or physical

handicaps. It is important to note that this is the result of developments elsewhere, resulting in the current situation. In the period before 1900 for example, a dozen epilepsy centres existed in the USA, such as the Ohio Hospital for epileptics, the Craig Colony in New York and the Massachusetts Hospital for epileptics. These institutions have all disappeared. The European Epilepsy centres therefore represent those centres that were able to adapt over time, taking on new roles and positions. Elsewhere such adaptation failed or was not accepted by governments.

4. How to assess the current situation?

Sometimes history is seen as a progressive movement, a development from 'old fashioned' to 'modern', from 'poor' to 'enriched'. Even the title 'from colony to community' given to me for this piece holds same connotation: from poor isolated individuals, living deprived in asylums to the fortunate recipients of modern medicine in the community. We must doubt, however, how much of this is true when we reflect on the current situation for epilepsy care. Of course it is preferable that epilepsy be treated in a local hospital in the community, when that is possible. However, in those cases where the epilepsy is complicated, seizure control is not achieved, or co-morbidities occur, when epilepsy has long-term or even permanent effects, a general hospital will lack the expertise and the facilities for multidisciplinary cure and care. Treatment in a general hospital is mono-disciplinary and when this fails the patient is referred to another department: psychology, dermatology, etc. (which does not necessarily have epileptological expertise). The same is true for general facilities such as the laboratory or the pharmacy: sufficient for routine use, failing when specific expertise is needed (which of course is not the role of a general pharmacy).

This is also a situation where epileptology as an expert function can become neglected—as has been seen in many countries. In the Netherlands, only one university hospital (Maastricht) has epilepsy as its priority. In some countries no epilepsy centres exist and none of the university hospitals have epilepsy as a specialism. In such a situation epilepsy can become a condition that can only be treated routinely. For those who do not need more than a repeat prescription, that is fine—but when seizures cannot be controlled, when cognitive co-morbidities or depression develop, when complicated side-effects occur, when difficult treatments must be used such a ketogenic diet, vagal nerve stimulation, deep brain stimulation or epilepsy surgery, then this situation is less than optimal. In such scenario, the emphasis on 'epilepsy in the community' will reduce the options for specialized centres to develop or to sustain themselves. Government policies, especially budgetary policies, will follow this mainstream approach and will emphasise the low-cost alternative of 'treatment in general hospitals' in contrast to specialized care. This will deprive many patients of the expertise and the facilities they need to treat their epilepsy and its co-morbidities effectively and holistically.

In the previous section, it was noted that in addition to short stay hospital facilities, most epilepsy centres also have a large number of long-stay residential beds. Here also government policies aim at moving from 'colony to community'. These are generally patients with severe refractory epilepsies and learning disabilities. This begs the question—does it really help these people to be transferred to homes for people with mental or physical handicaps? The only difference for them is likely to be the lack of facilities for optimal care of their epilepsy.

5. What is the future?

Epilepsy treatment and epilepsy care have developed considerably over the years and the situation is completely different from the time of the colonies with bromide, fresh air and labour as the

only treatment options. It is now possible to choose among more than 15 different type of antiepileptic drugs, all with different mechanisms of action, different indications, different effects on seizures and different tolerability problems. Some of these drugs are only effective for specific syndromes or may even aggravate seizure frequency or seizure severity. As outlined in the papers by Williams and Cross, there are different forms of the ketogenic diet; there are also different forms of neuro-modulation, of which vagal nerve stimulation is the most commonly used. As discussed by Wilson and Engel, epilepsy surgery is available in most developed countries and the type of surgery has developed from temporal resections only to a spectrum of treatment techniques. Diagnostic options have increased dramatically since the introduction of high fields magnetic resonance imaging. There is much more knowledge about the impact of epilepsy on neurocognitive functions, and there are options to prevent effects on learning and future occupational possibilities. Social and psychological facilities have been developed that are tailored to the needs of patients with epilepsy.

Such complexity is not needed for every patient with epilepsy. About 45% of newly diagnosed patients will react favourably on the first antiepileptic drug, coming to and staying in remission.³ For such patients neurological control in a general hospital is sufficient. However, the remaining large percentage of patients need specialized epilepsy care in some form. Specialism and expertise only develop with sufficient critical mass. In other words forms of centralized care in the form of epilepsy centres will always be necessary. This is not a plea to return to the colonies, but it is a warning that the cry for 'epileptology in the community', when translated as 'epilepsy must be treated in general hospitals', will deprive the majority of the patients of specialized expertise and care.

A disadvantage that the 'older' epilepsy centres in Europe have is their disconnection from universities and university hospitals. The claim of being 'Centre of Competence' and 'Centre of Excellence' outside the facilities that have research, innovation

and expertise as their core business is a weak point. Also in the much more complex current situation it will be extremely difficult for such centres to maintain all facilities (MRI, emergency facilities, operation theatre) as state-of-the-art.

These problems can be solved by combining epilepsy centres with university hospitals. In such a situation the epilepsy centre becomes the epileptology specialism of the departments of neurology and neurosurgery of a university hospital. This situation guarantees specialized care, offers epileptology the critical mass to develop further and connects it with the powerful resources for research and innovation and with the high-tech possibilities in university hospitals. This is actually the direction in which most of the epilepsy centres in Europe are evolving: the combination of the residential setting in Chalfont with hospital facilities (The National Hospital for Neurology and Neurosurgery) and facilities and university (Institute of Neurology of University College London) was one of the first examples, soon followed by similar developments in Switzerland, Norway and the Netherlands.

Medical care: 'from colonies to specialized academical centres for epileptology, supplemented by good standard care in general hospitals and in homes for patients with chronic epilepsy' would have been a too complex title for this article, but a much more accurate one.

Conflict of interest statement

None declared.

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