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Suurmeijer, Th.P.B.M.; Aldenkamp, A.P.; Heisen, T.W.M.; Overweg, J.; Renier, W.O.; Sie, O.G

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**THE ORGANIZATION AND UTILIZATION OF
A CASE REGISTER ON EPILEPSY**

Th.P.B.M.Suurmeijer^{1,2,3}, A.P.Aldenkamp^{4,6}, Th.W.H.Heisen⁴, and J.Overweg⁴, W.O.Renier⁶,
and O.G.Sie⁷

- 1 Department of Health Sciences, University of Groningen, Groningen
- 2 Department of Sociology, University of Groningen, Groningen
- 3 Northern Centre for Health Care Research, University of Groningen, Groningen
- 4 Meer & Bosch, Special Epilepsy Centre, Heemstede
- 5 Department of Developmental Psychology, University of Leiden, Leiden
- 6 Interdisciplinary Centre for Child Neurology, Academic Hospital, Nijmegen
- 7 Department of Neurology, Academic Hospital, Groningen
The Netherlands.

Address correspondence to:
Th.P.B.M.Suurmeijer, PhD.
Medical Sociology
Northern Centre for Health Care Research
University of Groningen
A.Deusinglaan 1
9713 AV Groningen
The Netherlands
Telephone: *3150 636279
Telefax: *3150 632406

ABSTRACT

About two years ago, representatives of "Meer & Bosch", a Special Epilepsy Centre in Heemstede, and of the universities of Leiden and Groningen (all in The Netherlands) started to discuss the formation of a case register on epilepsy in the northern part of the country. This follows the initiative to establish a case register in the southern part of The Netherlands.

The formation of such a register can be considered as an important initiative as it gives the opportunity to provide a more reliable and valid insight in the epidemiological aspects of epilepsy and, based on further research, insight in the use of health care facilities and in the secondary effects of epilepsy on the persons involved.

The registration of patients will start in the autumn of 1993. The next steps will be: the collection of further basic data on medical and psychosocial functioning of the patients, followed by fundamental and applied medical, epidemiological, psychological and sociological research on both secondary effects of epilepsy and patterns of use of health care facilities.

The organization and the possibilities concerning the utilization of the case register will be described.

Keywords: epilepsy, case register

Running head: Epilepsy Register Groningen

THE ORGANIZATION AND UTILIZATION OF A CASE REGISTER ON EPILEPSY**INTRODUCTION**

The primary reason to start the development of a case register called 'Epilepsy Register Groningen' (ERG), was the deeply felt need for a better data base than is mostly available or used in epilepsy research.

From the reviews of Rutgers (1988) and Shorvon (1990), it appears that incidence rates vary roughly from 11 till 134 per 100.000 per year and point prevalence rates from 1.5 till 10 per 1.000 of the population. In The Netherlands, estimates of prevalence rates vary from 0.29 to 0.79% [Bongers, Coppoolse, Meinardi, Posthuma & Van Zijl 1976; Centraal Bureau voor de Statistiek/Nederlands Instituut voor Maatschappelijk Werkonderzoek 1990; Metsemaker, Höppener, Knotterus, Bergers, Franssen, Köhlen & Ruyters 1990 ; Nijmeegs Universitair Huisartsen Instituut 1985).

These variations in incidence and prevalence rates found are partly caused by definitional differences between researchers: what is epilepsy? what is measured: life-time epilepsy, active

epilepsy or epilepsy alone? (Shorvon 1990; Verity, Ross & Golding 1992). But undoubtedly, an important cause of these variations can be attributed to *how* data were collected, more precise to the type of data base and sampling procedures.

EPILEPSY AND QUALITY OF LIFE

Accurate estimates of incidence and prevalence rates are not a goal in itself. They are important because of the need of research into the 'prognosis of epilepsy' in a medical as well as in a psychic and social respect. It enables us to measure the success of the treatment and to determine the nature and extent of the facilities required for the treatment of epilepsy.

However, information on the medical, psychic and social situation i.e. the '*quality of life*' of people with epilepsy, often gives a biased i.e. one-sided picture. In general, most studies show an underrepresentation of people with milder forms of epilepsy, those who have been seizure-free or those who are no longer undergoing treatment (Gudmundsson 1964; Hauser, Elveback & Kurland 1967; Hauser & Kurland 1975; Pond & Biddle 1959/1960; Pond, Biddle & Stein 1960; Zielinski 1974). Generalizations based on the findings in one-sidedly composed groups are, therefore, not very reliable. Such studies often suggest descriptions of 'the epileptic patient' and contribute to maintaining preconceived ideas about people with epilepsy (Mulder & Suurmeijer 1979). Consequently, there is an urgent need for research on more 'normal populations' of people with epilepsy (Suurmeijer 1991) for which a good registration of 'cases' is a 'sine qua non' (Vriends & Knipperds 1992). To this end, the construction of a more comprehensive data base in the form of an epilepsy case register was considered an important tool.

EPILEPSY CASE REGISTER GRONINGEN - ERG

The health policy of the Dutch Government is characterized by an increasing interest in chronic diseases. *Quality of life* as well as *quality of care* are the most important areas of concern (Council for Health Research 1990, 1991; Ministry of Welfare, Health and Cultural Affairs 1989, 1991).

However, as mentioned previously, an accurate and reliable estimate of the size and composition of the 'group at risk' is lacking in The Netherlands. The development of an epilepsy case register can fulfil the need of more precise information and insight in these areas.

About ten years ago, in the southern Netherlands (in the province of Limburg), an epilepsy register was started (Van der Lugt 1989; Kruijen 1989; Bergers 1989). Presently, this register is hardly functioning anymore. This has probably been caused by organizational factors. In particular, two factors seemed to be relevant. One factor concerns the absence of sufficient manpower responsible for the collecting of information an registration (*continuity of personal*).

Moreover, the register probably required too much information of the medical specialists (*continuity of information*). This made too great demands on their time, leading to non-response and inaccurate and unreliable information.

Based on these experiences, we decided for a stepwise procedure and to start with a '*low profile*' epilepsy case register in order to acquire as large as possible a response from the medical specialists. We ask them as little information and time as possible (see below).

Furthermore, from the beginning an ERG-board (of the 'Foundation ERG', 1992) was formed, consisting of professionally interested persons; a secretary was appointed who is responsible for the collecting of basic information and the updating of this information on a regular basis while the recording and storing of the data into the computer was delegated to a scientific research institute of the University of Groningen (the Northern Centre for Health Care Research - NHC). Finally, we decided to start our registration in a small geographical region i.c. the province of Groningen in the northern Netherlands. In the future, geographical extensions of the recruitment area will, of course, be considered but only after the present-day register has proven to be successful. Also, a revival of the already existing register in the southern Netherlands is an interesting option with possibly joining the databases in the future.

THE PROVINCE OF GRONINGEN: POPULATION AND HEALTH CARE SYSTEM

The province of Groningen has 555.200 inhabitants. The composition of the population by age and sex is, roughly speaking, more or less the same as in The Netherlands as a whole (Table 1). Based on the three most recent prevalence studies in The Netherlands, a prevalence rate of 0.75% seems to be realistic. This means that about 4,200 people with epilepsy are living in the province of Groningen (with a range of 2,200 to 5,500 considering the prevalence rates mentioned before by Rutgers and Shorvon).

Table 1. *Population in the province of Groningen and in The Netherlands, by age.*

Age	Groningen	The Netherlands
0-19	23.6 %	24.9 %
20-64	61.9 %	62.2 %
≥ 65	14.4 %	12.9 %
	(N = 555,200)	(N = 15,129,200)

Source: Centraal Bureau voor de Statistiek 1993, p. 52.

Generally speaking, the family doctors refer patients i.c. people with epilepsy mostly to a neurologist, child neurologist or paediatrician. Otherwise, they are known at the inpatient or outpatient departments of general hospitals, nursing homes or institutions for the mentally disabled.

The province of Groningen has 241 family doctors, 25 (child) neurologists, 53 paediatricians, five general hospitals, 13 nursing homes (with a capacity of 2,171 beds: for 1063 psychogeriatric and 1027 somatic patients) and four institutions for the mentally disabled.

PROCEDURES TO COLLECT BASIC INFORMATION AND PRIVACY REGULATIONS

It was decided to collect patients with epilepsy primarily via the medical specialists treating epilepsy patients and via nursing homes and institutions for cognitively or mentally impaired persons. But the GP's and pharmacists will also be asked to cooperate (see below): a set of professionally designed brochures in which aim, use and procedures of ERG is shortly explained, will be sent to them with the request to give these brochures to epilepsy patients or to their parents when they appear in the GP's practice or when the pharmacist delivers anti-epileptic drugs (AED).

As has been mentioned, the Epilepsy Register Groningen will collect *basic information* during the first step of the procedure. This information will be gathered via the medical specialist. This information concerns patient-based data:

- name, address and telephone number, birthday and sex of the patient;
- name and address of specialist and type of specialism;
- name and address of family doctor;
- diagnosis 'epilepsy certain' or 'possible epilepsy';
- year of diagnosis.

Whenever the medical specialist sees a patient with epilepsy in his practice, he writes down the name of the patient on a small writing-block, especially developed for this purpose. At regular times, the secretary of ERG will collect these names and the basic information mentioned before from the specialist's secretary.

Next, a letter is sent to the patients explaining the aim of the register and asking permission to be included in the registration system. By signing a '*letter of informed consent*' the patient/parents agree(s) to be included. For epidemiological reasons, sex, birthday and 'epilepsy certain/possible' will also be registered if the patient refuses to be included in ERG.

To warrant the privacy of the patients and the legitimate use of the epilepsy case register, a '*privacy code*' (Privacy-reglement 1993) is made, which is in agreement with the Dutch privacy laws, and a '*Committee of Inspection*' is installed, consisting of persons of the medical specialia-

lists organizations, the institutions, and of the Dutch Epilepsy Patient Organization (Epilepsie Vereniging Nederland - EVN).

Of course, patients may also announce themselves to the Bureau of ERG. For these patients, the same data will be collected from their specialist after the patient's written permission to do so.

Everyone, included in the case register, will be removed immediately from the register, whenever he/she wants. The medical specialist will be informed when one of his patients is included in studies in subsequent steps of the register.

To keep the participating doctors informed, every six months a newsletter will be published, for example, about the number of registrations, types of researches and research results and other information considered important.

USE OF THE EPILEPSY REGISTER GRONINGEN; CONCLUSIONS

After the basic information is collected, additional information about some medical and social parameters, will be gathered by the board of ERG. Medical information, for example, about the type of epilepsy, type(s) of seizures, medication used, seizure-free periods, etcetera, will be collected via the files of the specialist in charge primarily by the secretaries of ERG and the specialist. 'Social data' will be gathered directly via the patient him/herself or his/her parents (e.g. information on education, occupation, family composition, age of parents/partner).

As implied before, the epilepsy register is primarily developed in order to create a reliable and representative sampling base which in turn should facilitate medical, epidemiological, psychological and sociological scientific and applied research of high standards. For example, investigations into the natural course of epilepsy, evaluative research into the effects and efficacy of different types of AED's, or research on the secondary effects of epilepsy on the quality of life of patients, their parents or partners. To this end, research proposals must be sent to the board of the Foundation ERG. After advice of the 'Committee of Inspection' the proposal is approved or rejected. After the research is carried out and the results have been published, the dataset is transferred to the Northern Centre for Health Care Research (NCH) mentioned before. This Centre will preserve the data for secondary analysis or for longitudinal purposes.

Finally, a professionally designed brochure is made. This brochure will be sent to all family doctors, neurologists and paediatricians in the province of Groningen. The brochure will be spread among patients via pharmacists, and the waiting-rooms of the GP's and specialists. To patients, who present themselves at the Bureau of ERG, this brochure will also be sent.

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