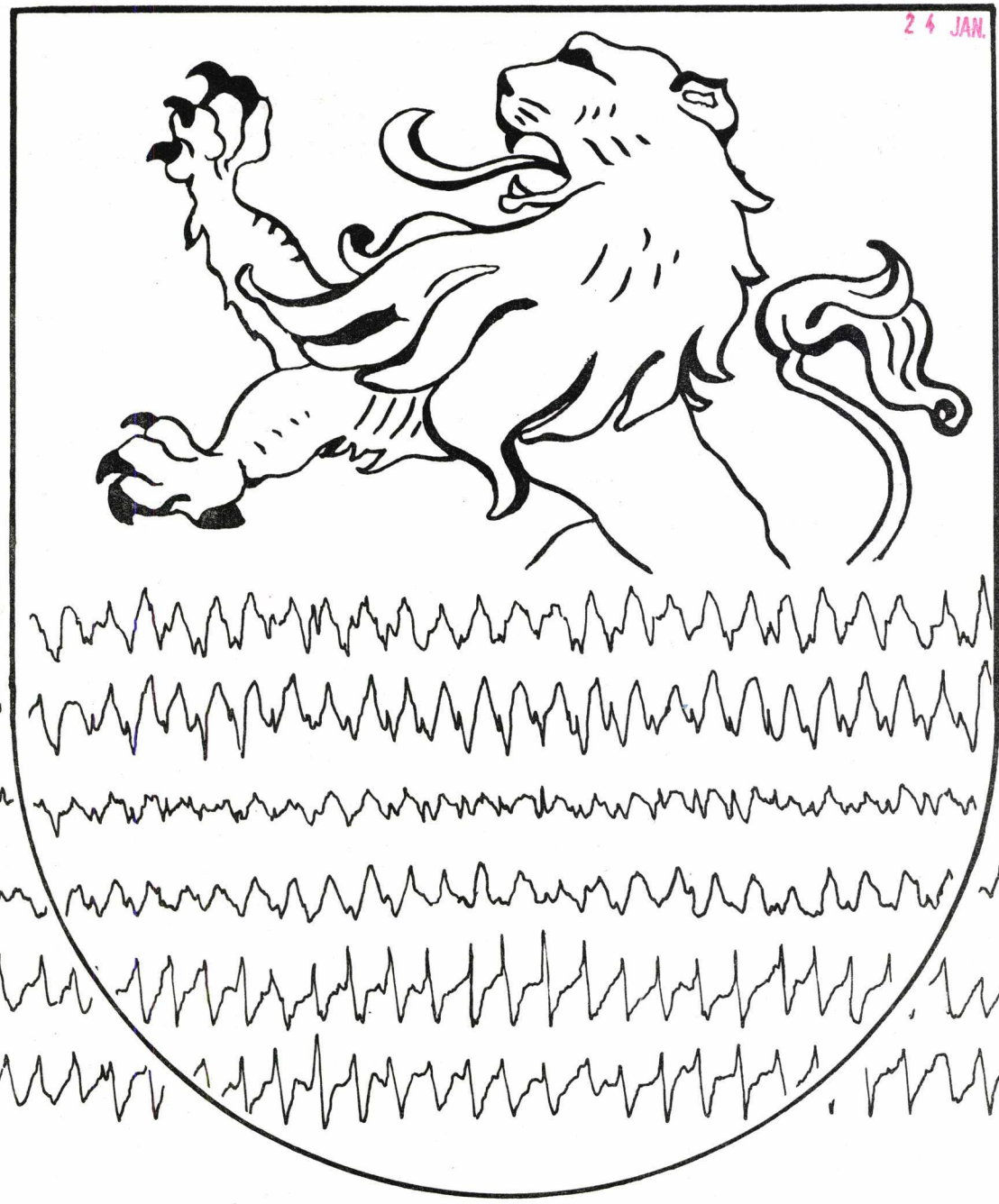


a survey of epilepsy
in zeeland
the netherlands

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1. INTRODUCTION.

In this study an estimate is presented of the proportion of the population suffering from epilepsy in the province of Zeeland, as gauged by the general practitioners at a particular instant, that is february 1973. There are several motives for this study: the need to know the prevalence and the outcome of the different discernable epilepsies; queries about the physical and psychosociological consequences of the epilepsies; and an endeavour to describe the structure of the health service with respect to the epilepsies and to measure its efficiency.

Zeeland was chosen as the object of the study for the following reasons:

the province of Zeeland is clearly distinguishable from its neighbouring provinces and has for the purposes of an epidemiological study of epilepsy a managably sized population of 300.000 inhabitants; a social worker specialized in the care of patients with epilepsy was available in this area to assist with the interviews; and an additional reason was the exceptionally low presentation of patients from this province amongst those hospitalized in special centres for epilepsy.

A longitudinal survey of the population would have exceeded the finances available for this study. For purely practical reasons therefore it was decided to retrieve the information needed through interviews with all general practitioners in this province. The GP's have been most cooperative: of the 119 doctors, 113 have conscientiously filled out the forms and answered the questions of the interviewer.

2. LITERATURE.

Recently the literature concerning the epidemiology of epilepsy has been extensively reviewed and discussed by Zielinski (1974) and Hauser and Kurland (1975). One has to conclude that the numerous studies are barely comparable. The outcome of an epidemiological survey appears to depend more on the method used than on the population studied. Hauser and Kurland mention discrepancies among the definitions of the disorder, case-ascertainment methods, classifications of several aspects and methods of data collection. In 1971 a workshop on the epidemiology of epilepsy held in Minneapolis, Minn., has contributed much to the understanding of the problems and the establishment of concepts in these matters, but whether this will lead to realisation of more uniform studies in actual practice is still doubtful.

A gross classification of the studies that have been published distinguishes general-practice surveys, clinical studies and true population (sample-) studies.

As for the last type, recent figures derived by Zielinski (1974), from a random sample of the inhabitants of Warsaw, show much higher prevalence rates than clinical studies would indicate (9.2 vs 4.2 per thousand), fig. 1.

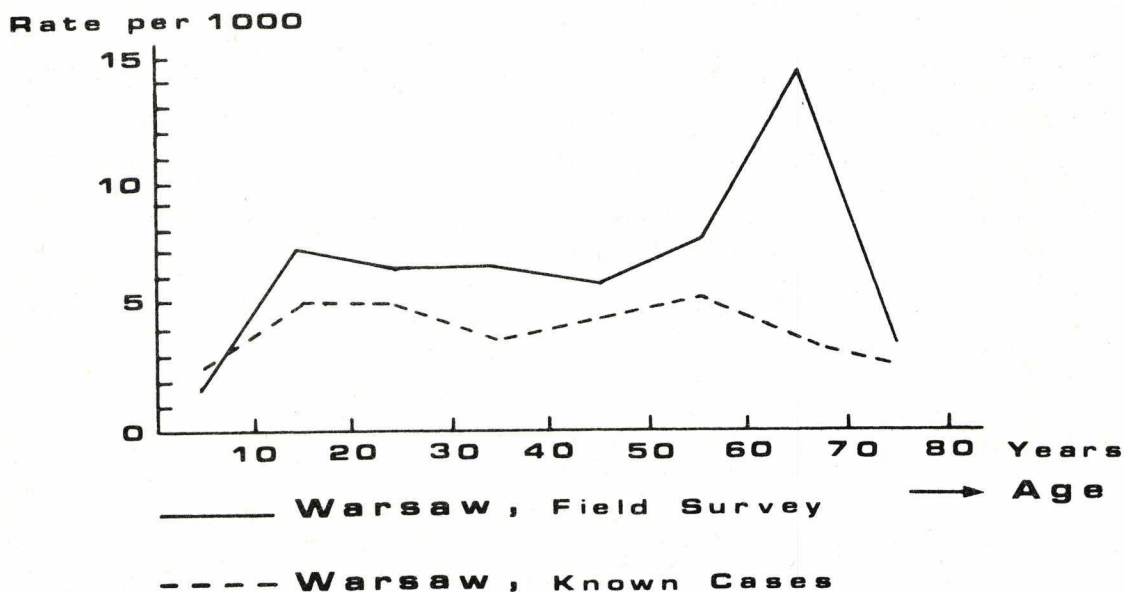


fig. 1: The prevalence rates of cases, known to specialty facilities ("known cases") compared with rates of epilepsy in a Warsaw population sample ("field survey"), Zielinski (1974).

As the author states, this is mainly due to cases of older patients with mild partial seizures with complex symptomatology, who do not apply for treatment.

The prognosis as regards freedom of seizures looks more favourable if derived from cases in the field survey than from those known to the medical profession even though the former partly lack medical help (resp. 42% vs 20% seizure-free after a two-year period).

The Rochester study (Hauser and Kurland, 1975) has been based upon 33 years of medical practice (Mayo Clinic) and the maintenance of a unit-record system by all doctors, except private physicians, in this area. Hauser and coll. assume that all patients with severe or complex illnesses will be referred for specialty consultation. Thus, virtually all cases recognized in this area should be included in their study. The results are in agreement with Zielinski's view that the prevalence of epilepsy increases with advancing age, but Hauser and Kurland do not specify the origin. As to the etiology, Hauser and coll. found 34% of the cases to be without apparent cause. From the known causes drug-withdrawal effects (including alcohol withdrawal) accounts for 17%, neoplastic and cerebrovascular diseases 7% each.

They also studied the percentage of remissions, defined as 5 years without seizure and without anticonvulsants at the latest follow-up. The observation of Rodin (1968) was supported: the percentage of remissions depends to a large extent upon the duration of the follow-up (resp. 30% at 15, 10% at 35 years after the onset of the illness). The remission rate in cases with identified cause did not differ from the rate without. Patients with partial seizures from the onset have somewhat lower remission rates.

Pond and Bidwell (1960) investigated epilepsy in fourteen general practices scattered over South-eastern England. The identification of the patients was made by the GP's, further collection of data was performed by a specialized social worker, which included interviews with the patients.

New cases were discovered by a second visit to the doctors after a year; a large part of these patients have also been visited by the social worker. By this method the over-all prevalence rate could be estimated, being 6.2/1000. Pond and coll. analyzed many features of the population of patients.

It appeared that the age-sex composition of the group was quite similar to the general population, but in respect of marital state the epileptic group contained rather more single persons (especially men) than the normal population and the male epileptic patients were in occupations of much lower 'social' class than the general male population.

	estimated age of onset of present illness											total all ages
	0 - 1	2 - 4	5 - 9	10 - 14	15 - 19	20 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 +	
males	19	12	12	14	9	15	12	9	3	8	5	118
females	12	14	19	21	19	6	6	9	8	7	6	127
PERSONS	31	26	31	35	28	21	18	18	11	15	11	245

Table 2: The age of onset of epilepsy, derived from a survey in fourteen general practices in Great Britain, Pond (1960).

The data on the onset of the illness (table 2) show a what is called 'slightly smaller' incidence rate for males of school-age (5-14 years) compared with those for females. In early adolescence (15-19 years) the difference is even more conspicuous, the rates for the female population being more than twice those for the male population. After age twenty the incidence rates for men exceed significantly those for women. Pond and coll. are wary of interpreting these differences as they feel that the figures cannot be adequately related to the population at risk. From the incidence rates derived from the new cases during the survey-year the same phenomenon is however even more clear, but the numbers are relatively small.

Compared to the results derived by Hauser and coll. the group of patients with 'a known cause for fits' is small (about one-third of the total group). Since the proportion of hospital-investigated was about the same in both the known and unknown subgroups, this seems not due to lack of special search for the origin of the seizures. However, Hauser and coll. mention 17% of cases due to withdrawal of toxic substances; this category is not mentioned at all by Pond and coll.

A separate paper by this author and co-workers, Pond (1959/60) is devoted to social and psychological aspects of epilepsy, discovered in the same survey. Behaviour disorders appeared rather common; about one-third of the patients of school-age had educational difficulties and about one-half of patients of employable age had job difficulties, especially in the younger age groups. Usually mental retardation and fits add to occupational difficulties. It is stated that temporal lobe epilepsy is responsible for most of these cases.

3. METHODS.

Through the regional health inspector all general practitioners in Zeeland were requested by mail to co-operate with this survey. Also forms were forwarded in which general questions about the medical aspects of each of their patients with epilepsy had to be filled out.

Next, the interviewer would arrange a meeting in order to complete a questionnaire as presented in table 3.

The acquired data have been subjected to standard statistical treatment, both for the complete set as for the subsets of the respective islands (Schouwen-Duiveland, Tholen, Noord- and Zuid-Beveland, Walcheren) and the main land regions of Oost-Zeeuwsvlaanderen and West-Zeeuwsvlaanderen.

	% item non-response	
QUESTIONS CONCERNING THE PRACTICE:		
in which part of Zeeland is the practice situated?	-	
what is the size of the practice (number of registered patients)?	-	
how long has the doctor been in charge of this practice?	-	
what is the number of patients with epilepsy in his practice?	-	
QUESTIONS CONCERNING THE PATIENT:		
general information:		
age, sex, and civil status	-	
is the patient a native of Zeeland?	-	
other background information:		
level of intelligence	4%	
level of education	17%	
level of occupation (also in comparison with his father's, c.q. his brother's occupation)	9%	
employment and living accommodation ('home situation')	4%	3%
information about the epilepsy:		
age at the onset of attacks	14%	
etiology	35%	
type of seizures	5%	
maximal frequency of seizures, from the onset till the present	39%	
frequency of seizures, present rate	12%	
information about medical attendance and treatment:		
has the patient been under treatment of a specialist/consulting physician?	6%	
has the patient been referred to a hospital (general hospital, epilepsy clinic, psychiatric centre) or out-patient department?	18%	
who is in charge of 'follow-up control'?	78%	
doctor's opinion about:		
behaviour and level of adaptation of the patient?	4%	
the origin of (possible) inadequate functioning of the patient?	7%	
information about welfare assistance:		
has the patient been assisted by institutions for welfare and social work (district-nursing, home help, municipal social service, general and specialized social work, special out-patient department for epilepsy, social psychiatric services etc.)?	7%	

Table 3: The items of the questionnaire and the percentage of item non-response (question answered with "unknown").

4. LIMITATIONS.

The results of this study have inherent limitations. Four sources of bias can be discerned:

1) in the doctor's catchment area a person may suffer from epilepsy, but the symptoms are insufficient to have caused consultation of a doctor and the symptoms have not been recognized as possibly epileptic.
 2) the patient is aware of his possibly suffering from epilepsy, but did not consult the GP in his area. From his experimental sample Zielinski, 1974, estimates the size of this group to be over 3/1000.
 3) the third category of patients did consult their doctor. The latter however, missed the diagnosis epilepsy. This may happen fairly frequently - obviously there is no consensus of which phenomena constitute sufficient basis to establish the diagnosis of epilepsy. Febrile convulsions in children are usually not reckoned amongst the epilepsies. Nevertheless it is well known that post aut propter app. 16% will later on develop true epilepsy (Bamberger and Matthes, 1959). Also some doctors pronounce the diagnosis of epilepsy after one, some after a minimum of two seizures.

Sometimes epileptic seizures are masked by the simultaneous occurrence of vasovagal attacks or hysteroid manifestations.

Finally, the present diagnostic methods do not provide foolproof evidence: one of the most important objective criteria, the EEG, will not show diagnostic features interictally in an appreciable percentage of cases.

4) The fourth category of patients not detected by the method used are those known to the GP, but overlooked at the time of the interview. The administration differs from one doctor to another and it is often rather difficult for a GP to retrieve from his files a patient treated for epilepsy many years ago. As a consequence of this mechanism 'active' cases will be overrepresented in this survey. The term active cases in this respect is not monointerpretable. This may mean patients who recently started to have seizures, but also patients who frequent their physician with unrelated problems, but thus remain in focus. Or patients may be remembered whose exceptional case history made a strong impression - and so on.

Apart from the bias in the material collected, other faults can influence the results. It is possible that data from a patient have been retrieved but in the process of the interview misunderstandings or administrative mistakes have occurred. There is no check on these failures.

In order to limit the number of questions, individual cases could not always be coded exactly. While obviously a compromise had to be reached between the wish of the investigators to obtain a detailed survey of the types of epilepsy and the fact that GP's will usually confine themselves to one or two subcategories of diagnosis. For the same reason for a number of questions with a clearly estimative character the doctor was asked to score on a five-point scale which was subsequently reduced to a three-point scale.

The authors realize that subjectivism also enters in their own selection of interrelations between the different items. However, the items studied were not only chosen because of their possible relevance. Certain relationships would have been worthwhile to know, but insufficient data were available for statistical evaluation.

After enumeration of all those restrictions, what merits remain in this investigation?

The investigation was started to answer questions about the prevalence and the course of the different types of epilepsy. Even though this survey cannot answer these questions accurately, it does show the way in which these problems are viewed by the GP. The office of the general practitioner is the 'porte d'entrée' of the health services. Knowledge about the handling of a medical problem at the port of entry compared with the guesstimate of the true size of the problem may provide a feedback for adjustment of the facilities available. As far as the questions about the social consequences of the epilepsies are concerned, it has to be kept in mind, that here again the GP often is supposed to be the first to refer the patient to the aid systems. It is however questionable whether indeed this system provides a patient with all the benefits that actually exist. Here again discrepancies between the information available from the GP and estimates by the specialists may be of interest.

5. GEOGRAPHIC AND DEMOGRAPHIC DATA.

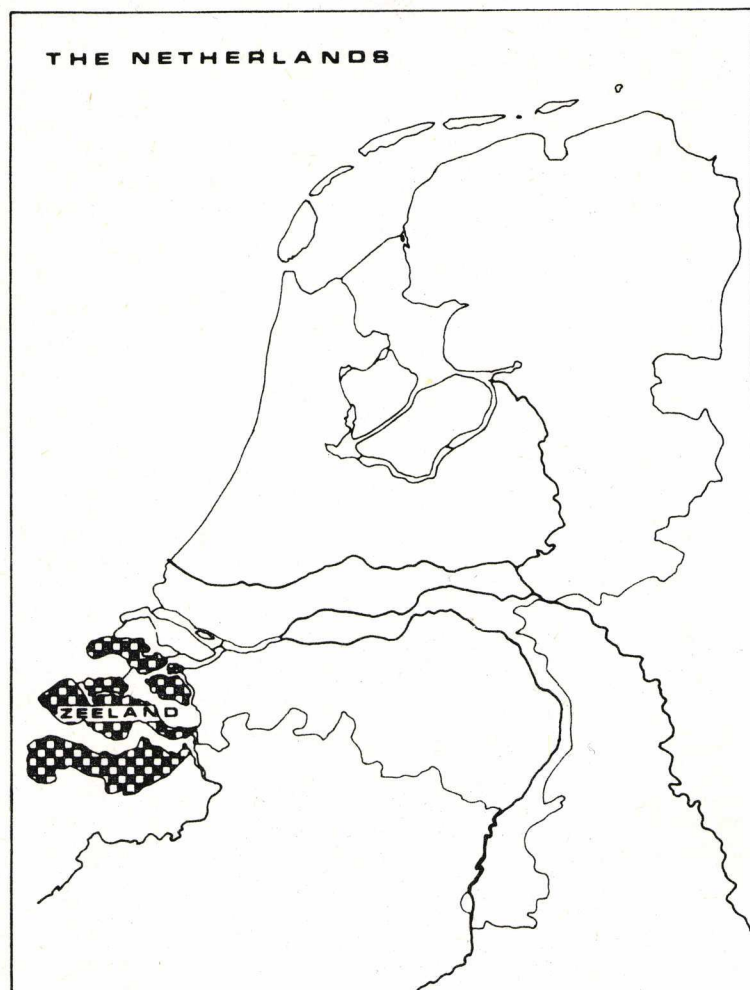


Fig.4: Situation of the province Zeeland in the Netherlands.

Zeeland, in the south-west of the Netherlands is the Dutch part of the deltaregion of the Schelde river (fig.4). It consists of islands and peninsulas.

The area comprises 6.7% of the total area of the Netherlands; 65% of this is land and 35% water. Since the floods of 1953 the islands have been interconnected and also connected with the mainland by a system of dykes.

The province is hardly urbanized: the larger towns do not exceed 50,000 inhabitants. 86% of the land is cultivated. The main sources of income for many years have been agriculture and fishing. In the last decennium, however, industrialization has altered this situation as thoroughly as it has altered the landscape. Hence, commerce and industry have become more and more important as shown in table 5.

ZEELAND	1960	1973
GROUP OF INDUSTRY:		
agriculture, fishing a.o.	23,460	10,870
manufacturing	19,930	30,795
construction	11,538	11,835
commerce	14,461	18,540
transport, storage and communication	8,158	7,700
public utilities and education	8,176	11,380
others	15,220	15,500
total econ.active people	100,943	106,620

Table 5: Economically active people, by groups of industry in Zeeland; absolute numbers (source: C.B.S.).

Like many parts of the Netherlands, a large part of Zeeland is below sea-level. In 1945, the isle of Walcheren was deliberately flooded in an attempt to expel the German occupants; in 1953 the great flood inundated the whole province. Even though some 2000 lives were lost and extensive damage of the cultivated area ensued, this flood did not alter appreciably the population profile, contrary to World-war II and the immediate post-war birth explosion (fig.6).

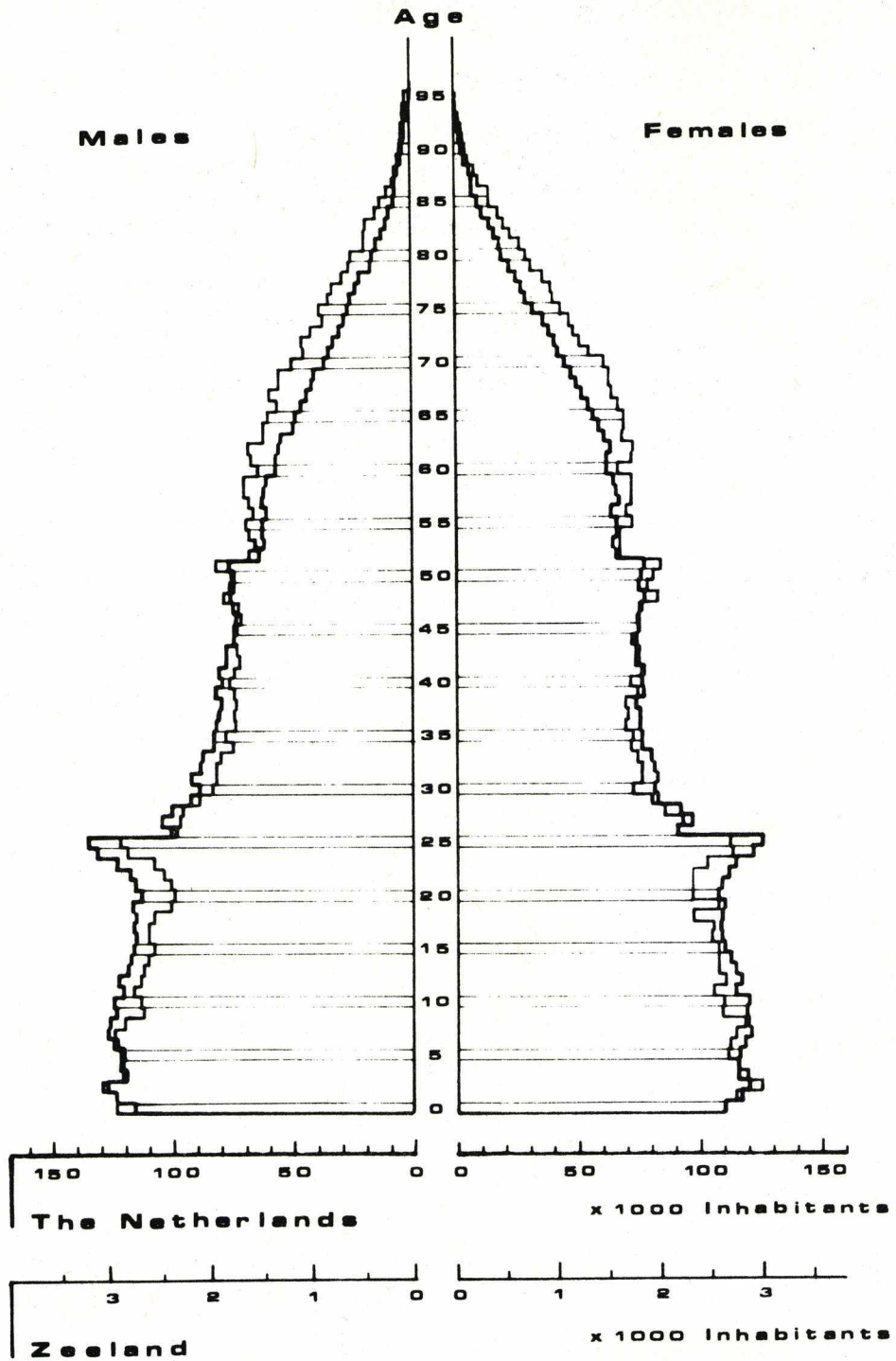


Fig. 6: The population profile of Zeeland shows a preponderance of older people in comparison with the total Dutch population (national census 1973, C.B.S.).

6. RESULTS, MEDICAL ASPECTS.

a. Prevalence of epilepsy in Zeeland.

Using the method described 835 patients suffering from epilepsy have been reported. Thus the over-all prevalence can be estimated to be 0.29%. This figure is distinctly lower than that published by Pond and coll., who surveyed the practices of a group of general practitioners in England.

Several other authors have found prevalence rates higher than the over-all figure derived from our data. The only other source of information on this matter in the Netherlands comes from the army. In table 7 the percentage of conscripts rejected from military service because of epilepsy are presented.

year	% rejected	% rejected due to epilepsy
1955	22	0.33
1956	21	0.36
1957	21	0.34
1958	20	0.37
1959	20	0.36
1960	21	0.43
1961	21	0.38
1962	22	0.39
1963	23	0.47
1964	23	0.48
1965	24	0.51

Table 7: Rejection of conscripts in the Netherlands (source: Inspector of the Army Medical Service).

It is clear that factors not related to the epilepsy may influence the outcome of the medical examination of the conscript, such as eagerness on the part of the candidate to stay out of service, or increased need of military man-power due to a threat of war.

Also these data are concerned with a particular group. For comparison: prevalence in the corresponding age and sexgroup found in the Zeeland-survey turned out to be 0.32%.

If the data are arranged according to the cumulative risk-rate (fig.8) a certain inconsistency can be noticed: it is to be expected that a higher age-group would show a higher prevalence. This apparently is not the case and several reasons might explain this phenomenon. A high mortality, which is not likely; and the ambiguity of the question put before the general practitioner to report all his patients suffering from epilepsy. It may be that some doctors did not include epileptic patients who had been free of seizures and off anti-epileptic medication. This may be due to misinterpretation of the question or due to the fact that the last seizure and last treatment had taken place so many years ago that the general practitioner was no longer aware of this particular patient. Also, contact with the adult patient with well-controlled epilepsy may be so infrequent that the cases have been overlooked (see also part 4, limitations).
Figure 8 suggests at least a cumulated risk of 0.4%.

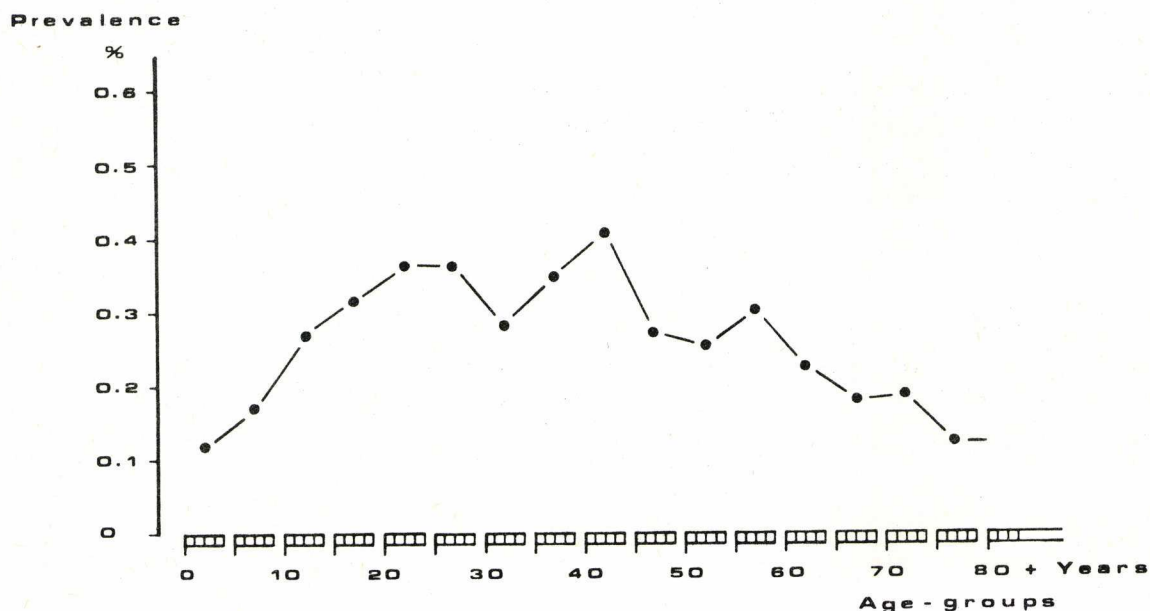


Fig. 8: Prevalence of epilepsy in Zeeland, by age (age-groups of five years).

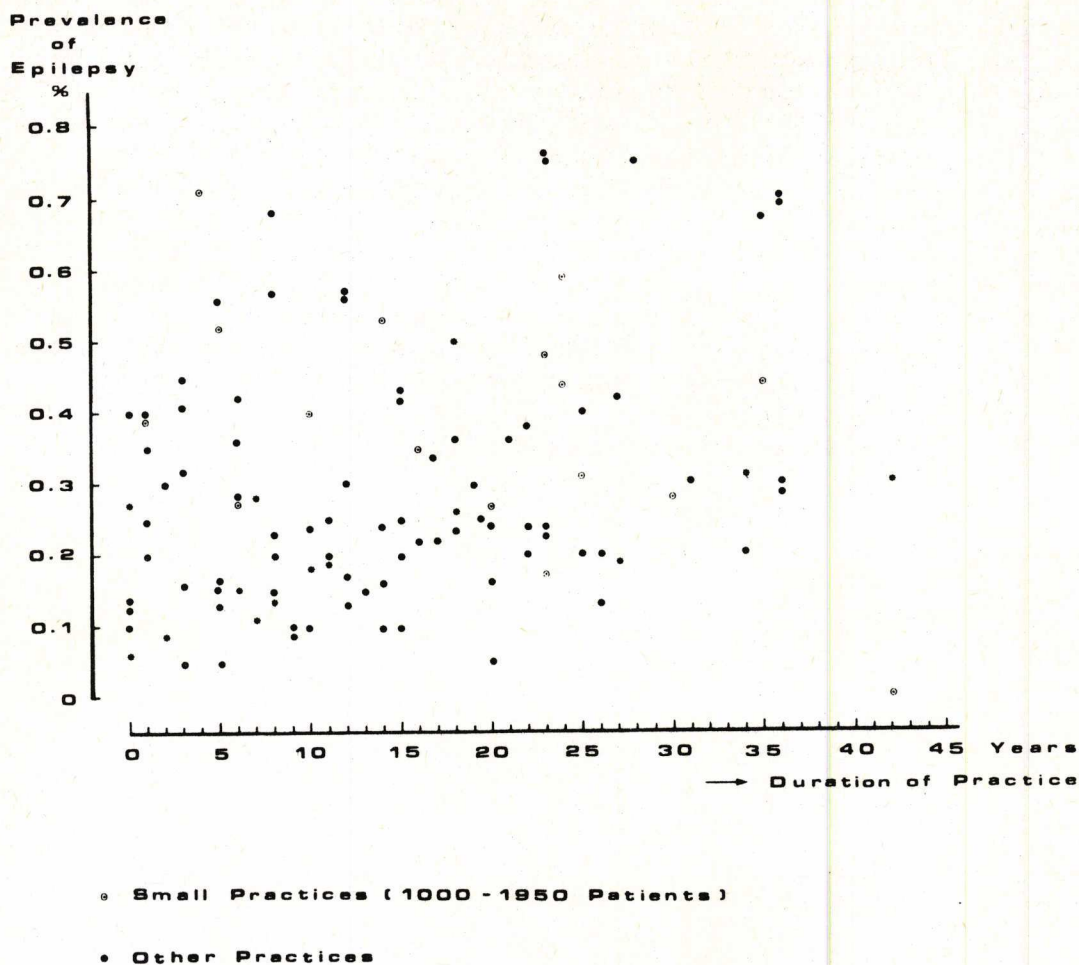


Fig. 9a: Prevalence of epilepsy for each practice in Zeeland, related to the duration of practice (abscissa) and the size of the practice.

Inspection of the prevalence rate per practice revealed that 13 doctors reported that not more than 0.1% of their patients were suffering from epilepsy. On the other hand 14 doctors have reported a prevalence from 0.5% to 0.7%. No significant correlation with size of practice or duration of practice was found (fig. 9a), although extreme low frequencies may coincide with a relative short duration of practice (table 9b). There is however a slight correlation with geographical situation (fig.10).

doctors with less than 0.1% patients with epilepsy:

	years of practice	size of practice	freq. of epilepsy(%)
range	0 - 42	1650 - 6000	0.0 - 0.1
median	9	2600	0.09
average	11	3050	0.07

doctors with more than 0.5% patients with epilepsy:

	years of practice	size of practice	freq. of epilepsy(%)
range	4 - 36	1400 - 6000	0.56 - 0.76
median	23	3000	0.68
average	20	2742	0.66

Table 9b: Features of practices reporting extreme low resp. high frequencies of epilepsy.

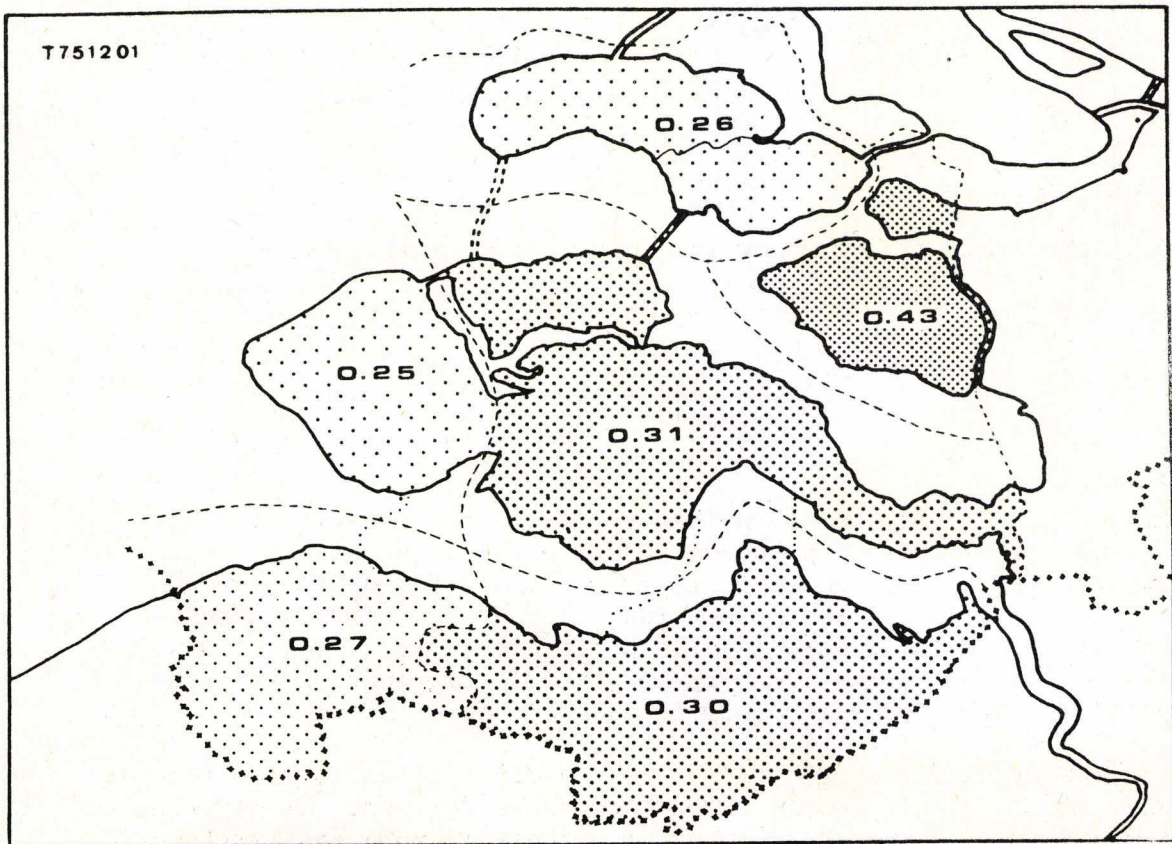


Fig. 10: Prevalence of epilepsy (%) in different parts of Zeeland.

b. Incidence of epilepsy in Zeeland.

In figure 11 the incidence-rates based on new cases (which came to the attention of the practitioners in the period 1967-1972) are represented, for each age-group of 5 years.

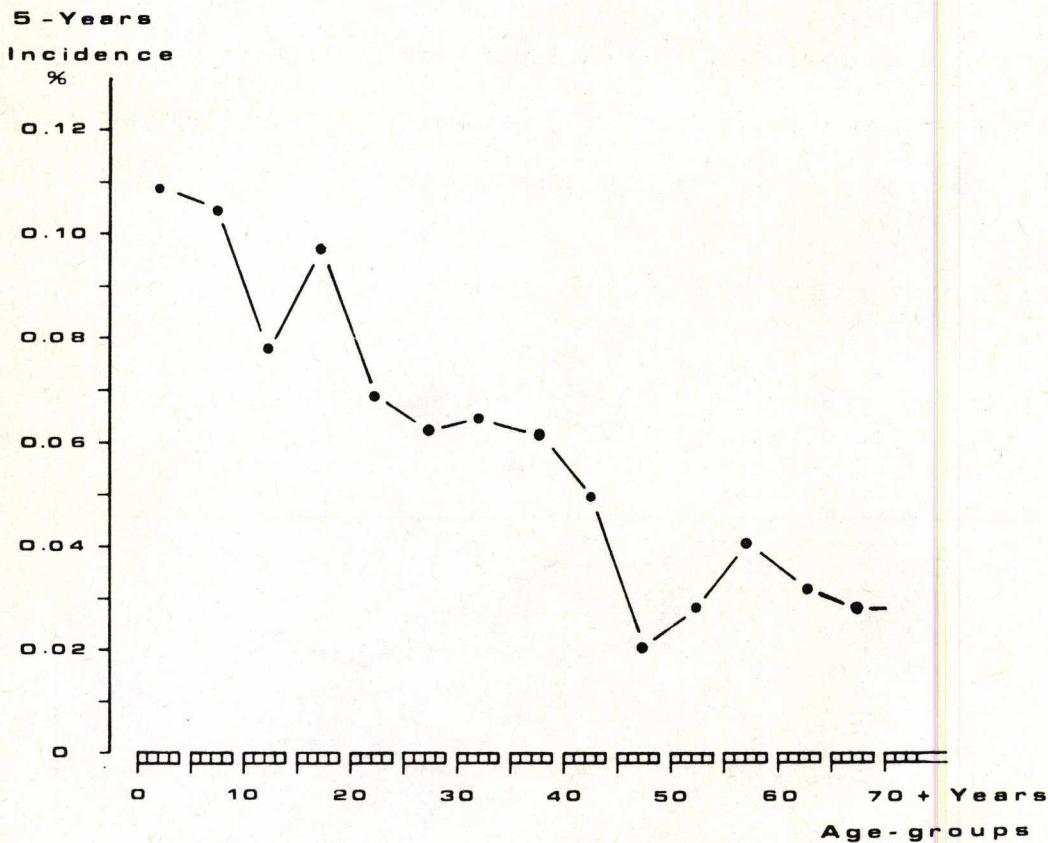


Fig. 11: Incidence of epilepsy in Zeeland.

The important difference in incidence between the age-groups 10-14 and 15-19 years hardly influences the prevalence graph. The high incidence rate in the age-group 15-19 years might indicate a high risk for head injuries and other traumata. However from figure 12 it becomes clear that there is also a difference according to sex. The elevation in the age-group 15-19 years is preponderantly caused by females, which suggests a hormonal influence.

In the age-groups above 25 years, the incidence rates for the female population are significantly lower than those for men. It may well be that women are less hampered by minor attacks or more easily blame other ailments like dizziness for the phenomena which they do not recognize as epilepsy and thus keep away from their physician.

Incidence-rates

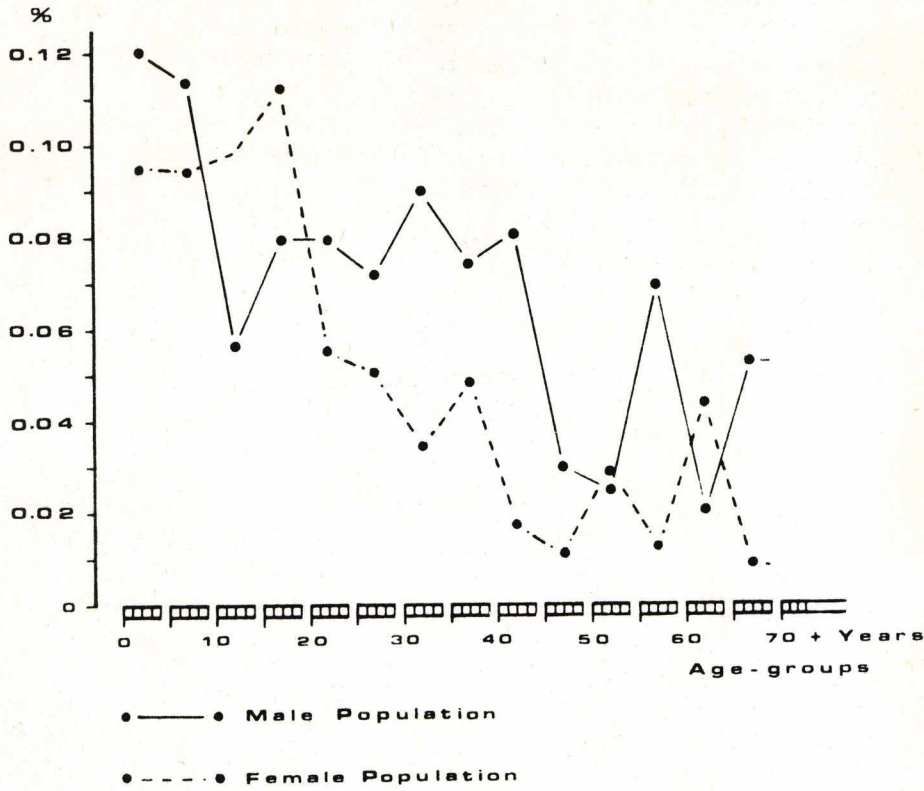


Fig. 12: Incidence of epilepsy according to sex.

Prevalence

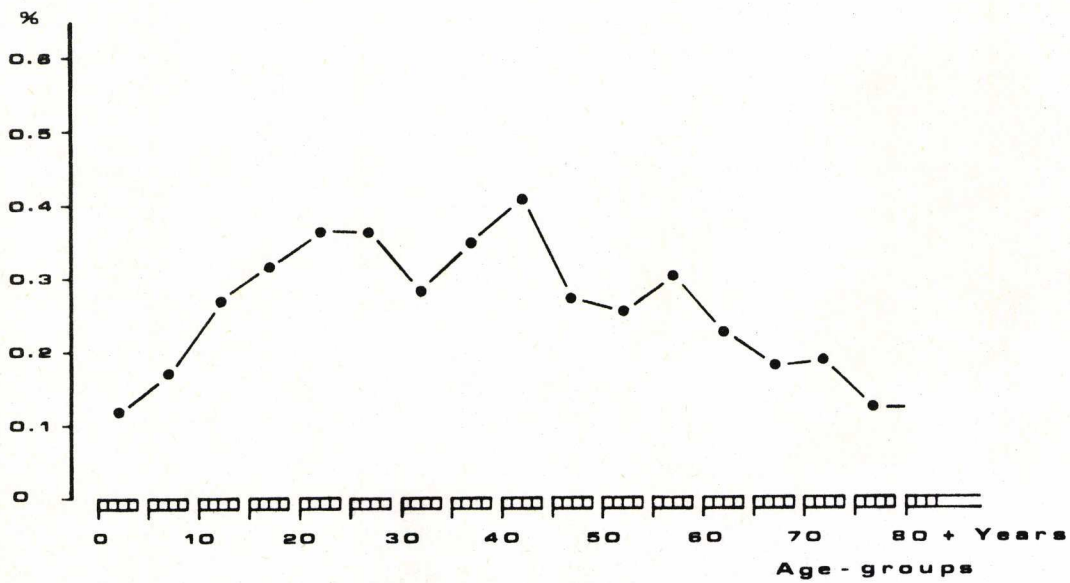


Fig. 8: Prevalence of epilepsy in Zeeland, by age (age-groups of five years).

The increase of incidence in the age-group 55-59 years apparently is due to the male population. This would fit the hypothesis of the role of cerebro-vascular accidents. In the age-group 60-64 years apparently the female population catches up.

The prevalence in the age-group 30-34 years is much lower than expected, especially as the incidence in the years 20-34 is almost constant.

The prevalence in the age-group 40-44 years rises clearly above the prevalence at 25-29 years. This again is not explained by the incidence in the age group 40-44 years. The prevalence at 45-49 years drops again below that at 30-34 years.

The incidence in the age-group 45-49 is also very low. The age-group 55-59 years again shows an elevation of the prevalence. This is matched by an increased incidence. Cerebro-vascular accidents may contribute to this increased risk.

In an attempt to find out whether incidence at older ages is mainly due to symptomatic epilepsies, the incidence rates have been recalculated according to a division in symptomatic and nonsymptomatic cases (fig.13). Only after 25 years the percentage of symptomatic cases increases appreciably. Yet even at its maximum only slightly over 50% of new cases are considered symptomatic.

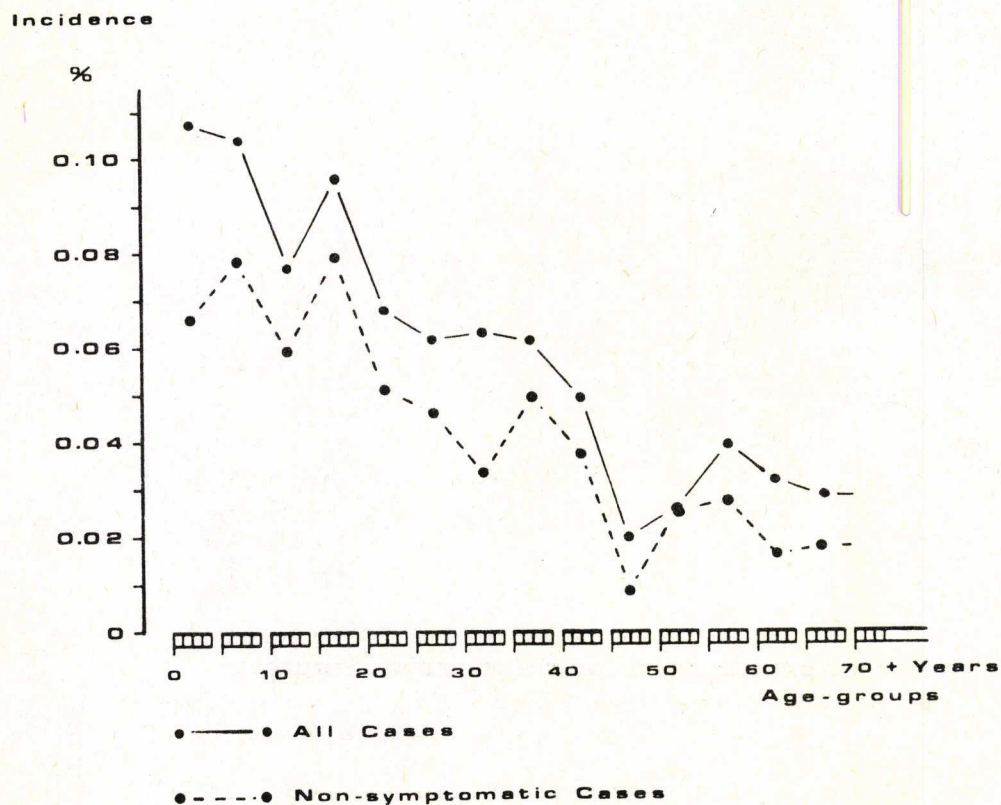


Fig. 13: Incidence of non-symptomatic cases ("genuine" epilepsy) in Zeeland.

In the next figure (14) an attempt is made to separate the prevalence of different seizure types. This has been restricted to three categories: generalized tonic-clonic seizures (grand-mal), typical absences, and all others including non-classified. The interpretation of this data is rather hazardous as we are uncertain of the accuracy of diagnosis. Another complication arises for similar reasons because it is not certain whether a patient is represented because of typical absences suffered during youth or because of misdiagnosed partial seizures with complex symptomatology, incurred at an older age. In the figures 15 and 16 the prevalence distributed according to the maximal frequency of seizures during the patient's history and the frequency of seizures in the year preceding the study are shown. This data suggests that indeed the increased prevalence of absences in the age-groups above 30 years as shown in figure 14 is due to a contamination of partial seizures with complex symptomatology and true absence-seizures. Of the latter one would expect a much higher frequency than the former.

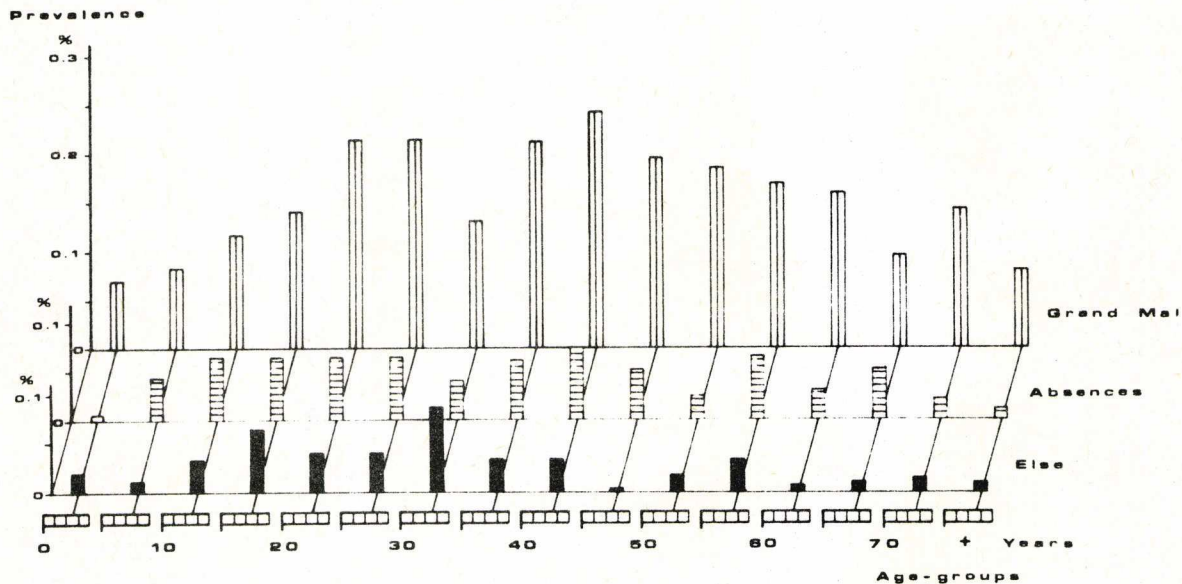


Fig. 14: The prevalence of different seizure types.

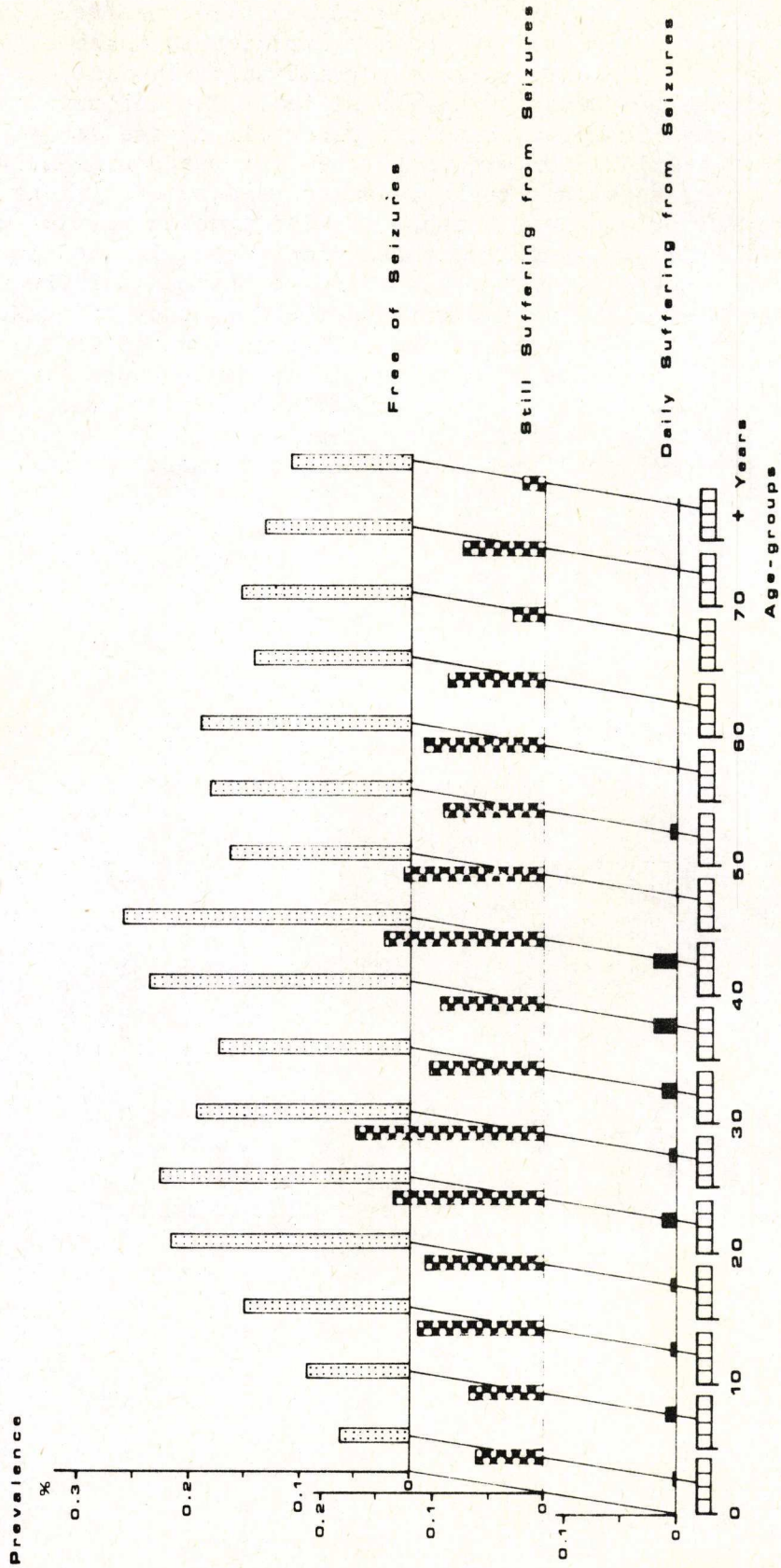


fig. 16: Prevalences, subdivided according to the current seizure frequency (that is, at the moment of the study).

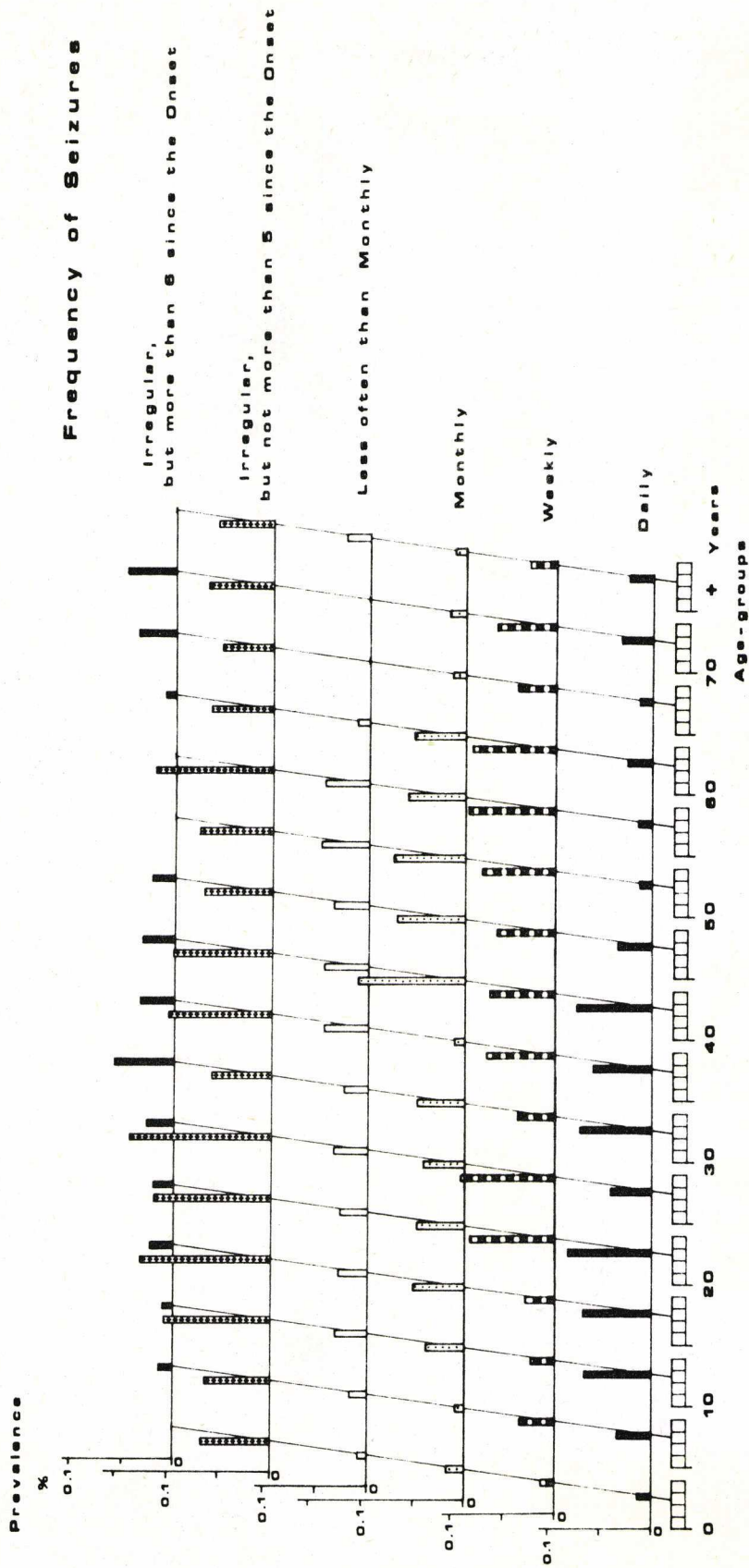
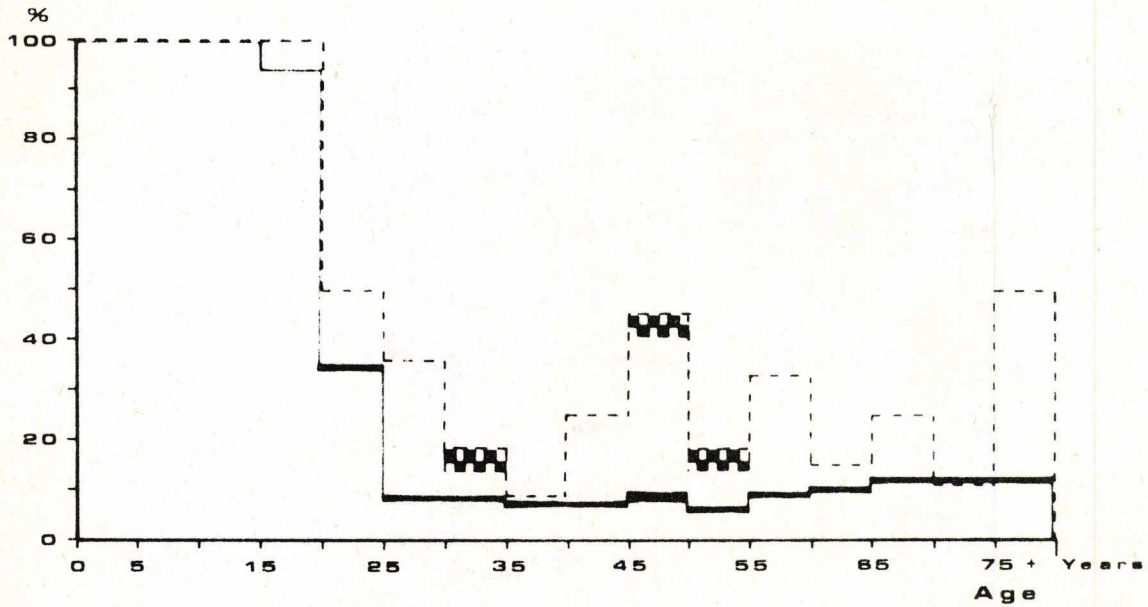


fig. 15: The prevalences of epilepsies, defined by the maximal frequency of seizures suffered during the course of the disease.

Fig. 17:

Epilepsy and Marriage

Female



- Epileptic Population
Percentage still Unmarried or Divorced
- ▨ Divorced
- _____ Population of ZEELAND
Percentage still Unmarried or Divorced
- Divorced

7. RESULTS, SOCIAL ASPECTS.

a. Epilepsy and marriage.

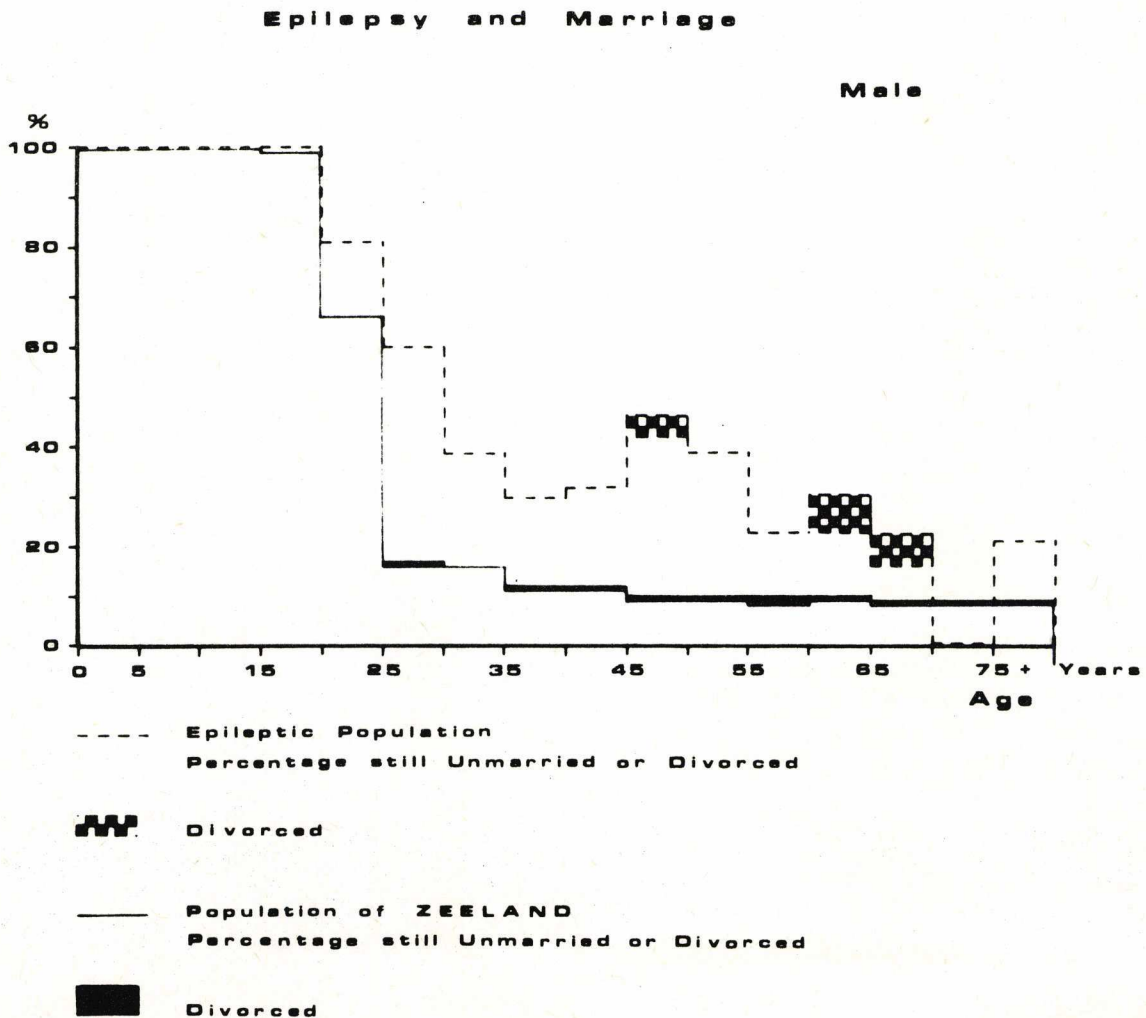
Marriage is an indicator of social functioning.

In the Netherlands only 14% of women and 26% of men of the age-group 20-25 years are still unmarried; these figures are 9% and 6% resp. in the age-group 50-55 years. For comparison, the figures of our group of patients: 50% and 80% resp. in the 20-25 years age-group and 18% and 35% resp. in the 50-55 years age-group.

One has to keep in mind that a small part of the general population is severely mentally retarded (idiots and imbeciles) and obviously the percentage of brain-damaged and consequently mentally retarded amongst the patients suffering from epilepsy will be somewhat higher.

Nonetheless this should not account for the high occurrence of unmarried people amongst those with epilepsy (fig. 17).

Fig. 17:



b. Intelligence, school and employment.

Especially these data are difficult to obtain from a survey where the only source of information is the general practitioner.

Nevertheless it appeared that most GP's were willing to give an estimate on these aspects of their patients.

In table 18 the intelligence-level and maximal frequency of seizures are compared. In the group suffering from generalized tonic-clonic seizures (grand-mal) lower intelligence and higher frequencies appear to correlate. This is not the case for the other types of seizures. The relatively favourable distribution of intelligence in the group suffering from daily seizures, may well be due to the part played by absence seizures, which would be in accordance with the good prognosis of this seizure type as reported by several authors (Lennox, 1960; Rodin, 1968).

In table 19 the highest level of education reached is presented. Of the whole group (n = 317) only those are considered about whom information was available (n = 264). Only six people could not attend school at all because of their mental handicap. However, one has to keep in mind that for this age group (20 years and older) the GP often will use his estimate of education needed for the job performed to classify the school attended. It may well be that a relatively large part of the unemployed are entered under "unknown".

In the same table (19) similar data for the total Dutch population is given. As can be seen the expected shift towards lower levels cannot be detected. This may be due to the non-response error mentioned above. Besides, first appearance of epilepsy after the age of 18 years will not influence schooling level, even though a detrimental effect on intelligence has resulted.

In table 20 the occupational situation is analysed in rather broad categories like "normally employed", "employed at social work provision schemes", "working incapacity", "unemployed". Approximately 9% are not able to work in connection with their epilepsy, 12% are employed in sheltered workshops, some 2% are still studying. Thus it appears that two-thirds of all men with epilepsy in the survey are normally employed.

	patients with epilepsy males, 20-65 years of age	population of the Netherlands, same sex and age group
normally employed	64 %	81 %
employed at social work provision schemes a.o.	12 %	2 %
unemployed	12 %	3 %
working incapacity (100%)	9 %	1.2%
attending school	2 %	12 %

fig. 20: Employment of economically active people.

level of intelligence:	seizure frequency				patients having (had) other kinds of epileptic seizures			
	patients, having (had) grand mal seizures							
	yearly	monthly	weekly	daily	yearly	monthly	weekly	daily
limited	26 %	47 %	54 %	58 %	32 %	34 %	40 %	24 %
normal	69 %	53 %	45 %	42 %	62 %	55 %	60 %	73 %
high	5 %	-	1 %	-	6 %	11 %	-	3 %
	100 %	100 %	100 %	100 %	100 %	100 %	100 %	100 %

table 18: The level of intelligence (according to the doctor) in relation to the predominant type of seizures and the maximal frequency of seizures reported during the disease.

educational level:	patients with epilepsy, males, 20-65 years of age	population of the Netherlands, same sex and age group
elementary	57 %	57 %
advanced elementary	29 %	33 %
secondary/ semi-higher	6 %	9 %
higher	3 %	2 %
unable to attend school	0.7 %	?
special school for mentally retarded people	4.4 %	?
	100 %	100 %

table 19: The educational level reached by adult, male patients in comparison with the population of the Netherlands.

HOME SITUATION:	epileptic patients 25 - 64 years of age	population of Zeeland same age-group
living with parent(s)	16%	6%
living with own family	62%	87%
living with other relatives, or with foster-parents	2%	4%
living on their own	18%	2%
living in institution	2%	?
	100%	100%

Table 21: Home situation of adult patients with epilepsy.

Age groups:	0 - 9 y.		10 - 19 y.		20 - 39 y.		40 + years		all ages	
	M	F	M	F	M	F	M	F	M	F
Adequate behaviour	82%	83%	71%	86%	72%	71%	77%	72%	75%	75%
Moderate behavioural problems	18%	17%	23%	13%	24%	27%	19%	24%	21%	23%
Inadequate behaviour	-	-	6%	1%	4%	2%	4%	4%	4%	2%
total	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Table 22: Qualification of behaviour of patients with epilepsy by the general practitioner.

c. Adaptation and home situation.

The home situation has been evaluated according to the categories shown in Table 21 compared with the total population of Zeeland. The majority of the adult patients have their own household, either single or married. In Table 22 the opinion of the GP is represented as to whether the patient is socially well-adapted or experiences difficulties in this respect. It turns out that almost 25% do have troubles. Men and women are equally represented; apparently occupational stress plays a minor role. The opinion of the doctor on the reason for possible malfunctioning of their patients is shown in Table 23. For about 70% of their patients the doctors felt that this question was irrelevant because the former were functioning normally. The majority of those who do not enjoy a normal life are handicapped (according to the GP) because of 'epileptic behaviour' and only very few because of their seizures.

	age group:					
	0 - 19y.		20 - 64y.		65 + years	
sex:	M	F	M	F	M	F
functioning adequately	72%	77%	63%	63%	73%	64%
not adequately	28%	23%	37%	37%	27%	36%
because of:						
<u>physical handicaps</u>						
frequent attacks	-	-	2%	2%	7%	5%
other physical handicaps	4%	3%	5%	3%	7%	9%
<u>mental handicaps</u>						
lack of intelligence	9%	8%	6%	12%	7%	5%
'epileptic behaviour'	11%	4%	15%	16%	11%	18%
other mental handicaps	7%	2%	13%	12%	13%	9%
<u>other reasons</u>	10%	8%	5%	11%	-	-
<u>overlap (multiple handicaps)</u>	12%	3%	10%	18%	17%	10%

Table 23: Doctors' opinion about the origin of possible malfunctioning of their patients.

8. EPILEPSY AND THE HEALTH SERVICE.

a. Medical attendance.

Obviously in this survey only those patients are encountered who have reached the gate of the health service, as the GP is often called. Beyond there are several options: either continuous care by the GP, without further consultation; advice from a specialist, but mainly care by the GP; further treatment by the specialist only. The use made of these options is presented in Table 24. Only some 10% of all cases are treated by the GP only, mainly these are older patients. The vast majority of cases are dealt with by the neurologists or both the neurologist and the GP. In spite of the fact that there is no epileptologist (here used in the restricted sense of neurologist or neuropsychiatrist attached to a special centre for epilepsy) available in Zeeland itself, over 10% do consult epileptologists in other provinces. The important influence of the pediatrician due to the early onset of about 50% of the epilepsies is also clear from his share in the pattern of healthcare (table 24). Especially for those families that are privately insured the pediatrician is himself often the first gate to the health service.

		all patients	patients under 15 years
		%	%
TREATMENT BY			
general practitioner	only	10	4
	jointly	32	32
neurologist	only	43	19
	jointly	35	34
epileptologist	only	10	7
	jointly	4	0
pediatrician	only	5	25
	jointly	8	34

Table 24: Participation of general practitioners and/or specialists in the actual treatment of the epilepsies.

In table 25 the groups of patients treated on outpatient-basis respectively inpatient-basis are compared. From this table the original incentive to study this problem, namely the minor use that is being made of special centres for epilepsy by the population of Zeeland, is corroborated.

	%
in-hospital treatment of epilepsy	58
general hospital	51
epilepsy clinic	6
other hospital	6
treatment in out-patient department	
of a general hospital	53
of an epilepsy clinic	14
never treated in either	15

Table 25: Percentage of patients with epilepsy in this study attending intra-mural and/or extra-mural services.

b. Institutions for social work and welfare.

Although the GP would not necessarily be informed about the use made by the patient of the social work and welfare facilities nevertheless many doctors appeared to be quite aware of these aspects.

Supply and demand of these services have a very complicated relationship. The boundaries between insufficient optimal and overconsumptive use are difficult to assess. The outpatient departments of the special centres for epilepsy offer both medical and social assistance. These nearly always go hand-in-hand and it is well nigh impossible to subdivide these patients according to whether they primarily visit these departments in order to receive social or medical help. It was found however that 90% of all those who obtained social help from the outpatient departments for epilepsy also received medical care therefrom. The importance of the geographic conditions in determining the percentage of patients who avail themselves of social facilities can be seen in fig. 26.

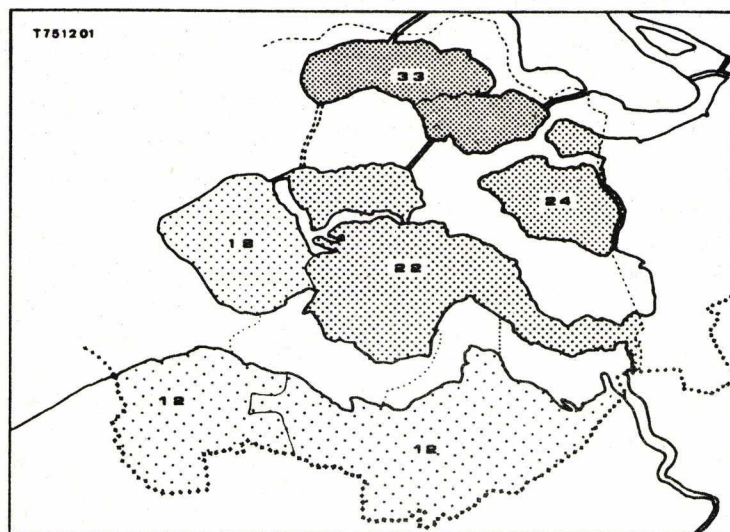


fig. 26a: Percentage of patients with epilepsy availing themselves of social work and welfare services.

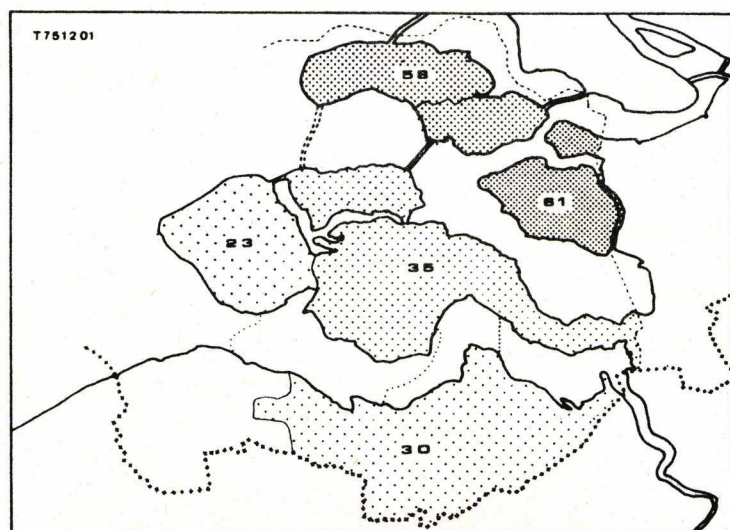


fig. 26b: Percentage of patients presented in fig. 26 who make use of the special facilities for people with epilepsy.

In Tables 27 and 28 the group that consults the special outpatient departments for epilepsy is compared with the remainder of patients receiving social help from other sources. As can be seen, the former are more handicapped regarding the severity of their epilepsy (expressed as 'frequency of seizures at the time of the survey'), although doctor's opinion is that this has hardly any bearing on the level of functioning of the patient. Grosso modo the patients consulting special outpatient departments are functioning more adequately than those visiting alternative institutions.

	patients consulting special outpatient departments	patients consulting various other institutions for social help
functioning adequately	47%	20%
not adequately	53%	80%
because of:		
physical handicaps:		
frequent attacks	7%	3%
other phys.handicaps	2%	13%
mental handicaps:		
lack of intelligence	6%	18%
'epileptic behaviour'	24%	24%
other mental handicaps	15%	31%

Table 27: Functioning of patients with epilepsy according to the judgment of their general practitioner attending respectively special facilities for people with epilepsy or general facilities.

	patients consulting special outpatient departments	patients consulting various other institutions for social help
suffering from frequent attacks (daily, weekly or monthly)	33%	17%
suffering from sporadic attacks	37%	30%
free of seizures	30%	52%

Table 28: Frequency of seizures as mentioned by the general practitioner respectively for patients attending special facilities and those attending general facilities.

Though it is not certain whether the primary motives for visiting a special outpatient department for epilepsy are medical or social problems, the first possibility seems most likely.

In Table 29 the relative importance is given of the institutions giving social care mentioned in this survey.

patients not receiving any social help	81%
patients receiving social help	19%
	<hr/>
total	100%
namely from:	
general social work	30%
municipal social services	6%
social psychiatric services	29%
special outpatient departments for epilepsy	35%
district nursing	1%
home help	6%
other services	11%
because of overlap (combined services)	- 18%
	<hr/>
total	100%

Table 29a: Percentage of all patients in this survey receiving any social help.

29b: Breakdown of types of social help.

9. CONCLUSION

The limitations of this study have been discussed in chapter 4. An outline appears of the medical, social and occupational situation of some 800 people suffering from epilepsy. It appears that about a quarter of such a population is in need of special attention in addition to the medical help 'as a matter of course'. Whether the present facilities are the most appropriate can only be answered by a specially designed study. The results contained in this paper give some indication where problems are located and which questions should be considered in order to plan a 'well-balanced' care system for people with epilepsy.

10. LITERATURE

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