

RETROSPECTIVE REVIEW OF DEATH CERTIFICATES OF PATHOLOGICALLY CONFIRMED
CASES

Details of 87 pathologically confirmed cases were forwarded to O.P.C.S. 79 certificates were found of which one does not relate to the named patient.

9
12

The table below is a breakdown of details on the certificates from the remaining 78 cases.

<u>Cause of death</u>	<u>No. of patients</u>	<u>Ia</u>	<u>Ib</u>	<u>Ic</u>	<u>II</u>	<u>Codings</u>	<u>No.</u>
Creutzfeldt-Jakob disease (CJD) (or equivalent)	37	16	16	2	3	333.9	29
						355X	4
						485X	3
						290.1	1
Subacute spongiform encephalopathy (SSE) (or equivalent)	15	11	2	1	1	781.7	6
						590.1	2
						485X	1
						334X	1
						323X	1
						450X	1
						281.1	1
						347.9	1
355X	1						
Other	26					20 rubrics	

(A list of rubrics and their meanings is appended)

Breakdown of 'other' category

	<u>No. of cases</u>
Pre-senile dementia	6
Encephalitis	3
Cerebral atrophy/degeneration	3
Cerebrovascular accident	3
Diffuse sclerosis	2
Bronchopneumonia	2
Parkinson's disease	1
Ataxia and dysphasia of uncertain origin	1
Medullary failure	1
Evacuation of subdural haematoma	1
Progressive muscular atrophy	1

The list of cases contained patients certified from the years 1962 to 1978. Although there were fewer cases in the 1960's the accuracy of certification has increased.

<u>Diagnosis on certificate</u>	<u>60's</u>	<u>70's</u>	<u>Total</u>
CJD/SSE	9	43	52
Other	23	55	78
Percentage	39%	78%	66%

However, as can be seen from the first table, there is a marked inconsistency in coding even if the diagnosis on the certificate is accurate. This is particularly true when the certificate mentions subacute spongiform encephalopathy. The reason for the inconsistency is that the codebook supplied with the 7th I.C.D. revision does not mention the condition and it is therefore classified under a variety of rubrics with 781.7 featuring prominently. It is of interest that not only is the diagnosis more accurate in the seventies but also the proportion of certificates mentioning SSE drops.

<u>Diagnosis on certificate</u>	<u>60's</u>	<u>70's</u>
SSE	4	11
CJD	5	37
Percentage	44%	23%

The intended retrospective study would be limited to the seventies and as certification is more accurate in this period the table below is a summary of the data excluding information from certificates from the sixties.

<u>Diagnosis</u>	<u>No. of cases</u>	<u>Codings</u>
CJD	32)	333.9 28
SSE	11)	781.7 5
		485X 4
		590.1 2
		290.1 1
		281.7 1
		323X 1
		460X 1
Other	12	

Summary

The purpose of obtaining this information was to ascertain the likely value of obtaining lists of certificates for rubrics 333.9 and 290.1 for the years 1970-1978 (In 1979 the 9th I.C.D. revision was introduced with a specific code for CJD and SSE).

It would be of value to obtain certificates under rubric 333.9 for these years and also certificates under rubric 781.7. It is unlikely that obtaining the same information for rubric 290.1, as was originally intended, would reveal more than a very limited number of previously unknown cases.

It might appear from the table that information on rubrics 485X and 590.1 would be of value. However these two rubrics are non-specific referring to bronchopneumonia and pyelonephritis respectively. Of the four cases under rubric 485 only two mentioned CJD and if lists were obtained for this rubric a number of cases would be missed because of inaccurate certification.

A further objective was to assess the possible value of obtaining information as to the frequency with which CJD was mentioned as a secondary condition for the year 1973. The table below shows the details of certificates in which CJD was mentioned as a secondary condition in the 1970's as a whole.

<u>Diagnosis</u>	<u>Classification</u>	<u>Coding</u>	<u>No.</u>
CJD	Ib	333.9	14)
CJD	Ib	290.1	1)
CJD	Ic	333.9	1)
CJD	II	485X	3)
SSE	Ib	485X	1)
SSE	II	450X	1)

)Certified as CJD
)Certified as primary condition

Only five out of 21 certificates mentioning CJD as a secondary condition were coded as to the primary cause of death.

Conclusions

The details of a number of previously unknown cases could be discovered by obtaining lists of certificates coded under rubrics 333.9 and 781.7 for the years 1970-1978. Lists of such certificates have already been obtained for code 333.9 for the years 1971-1976 and a total of 71 previously unknown cases were obtained.

The exact information required would be:

1. Copies of certificates coded 333.9 for years 1970, 1977 and 1978
2. Copies of certificates coded 781.7 for years 1970-1978
3. Copies of certificates coded 331.5 and 046.1 for the year 1979 (this is the 9th ICD revision in which CJD and SSE are individually coded)
4. Copies of certificates under codes 333.9 and 781.7 for years 1970-1978 and copies of certificates under codes 046.1 and 331.5 for 1979 from the General Register Office in Scotland. I have contacted this office and it has been confirmed that it is possible to obtain this information.

If this is carried out details of approximately two thirds of the cases in the 1970's would be obtained. Information from other sources should enable details of a proportion of the 'missing' patients to be obtained.

Costs

An estimate of costs has been obtained from O.P.C.S. and the General Register Office for Scotland for the originally intended search of certificates. The revised retrospective study would be more expensive but should still be well within the limit of £2,000 previously suggested. Exact estimates shall be requested so that the retrospective study can be started if the above suggestions are approved.

Codings

7th ICD revision	0.334	Other and ill-defined vascular lesions affecting the CNS
	4.355	Other diseases of brain
8th ICD revision	281.1	Other vitamin B ₁₂ deficiency
	290.1	Pre-senile dementia
	323	Encephalitis, myelitis and encephalomyelitis
	✓333.9	Other hereditary and familial diseases of nervous system (unspecified)
	347.9	Other diseases of brain (unspecified)
	450	Pulmonary embolism and infarction
	485	Bronchopneumonia
	590.1	Pyelonephritis, pyelitis and pyelocystitis
	781.7	Encephalopathy
9th ICD revision	046.1	Slow virus infections of CNS (.1 CJD)
	331.5	Other cerebral degenerations (.5 CJD or subacute spongiform encephalopathy)