Hospitalization rates for Alzheimer's disease

by

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Abstract

Procedures of data collection on hospitalizations for Alzheimer's disease are compared among the countries of the European Union. Data were obtained from the national institutes of statistics and ministries of health. Information relates to the type of health institutions collecting data in a systematic way, procedures of codification and publication, collection of associated diagnoses, and characteristics of the patient. Coverage and coding practices differ markedly between countries. Where possible, levels of hospitalization rates for Alzheimer's disease (AD) are assessed. Hospitalization rates for AD increase significantly with age and do not differ much between males and females. Codification of diagnoses according to ICD-10 leads to a much lower level of hospitalization rates than following ICD-9. Data on outpatients and from private hospitals are presently not available and should be collected by the health system.

Keywords

Alzheimer's disease, codification, hospitalization rates.

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Introduction

Alzheimer's disease (AD) is a form of dementia affecting the cerebral cortex. This neuro-degenerative cerebral disease leads to insidious and progressive brain destruction. Symptoms of AD include the decline of memory functions, personality changes, deterioration of language functions, impairment in visual and spatial tasks, and finally motor dysfunctions. In advanced cases, personality disintegrates and the person becomes totally dependent or bedridden. Present diagnostic protocols provide different levels of diagnostic certainty by classifying cases as definite AD, probable AD, or possible AD. In some cases the clinical features of AD are such that only a post-mortem examination can confirm the diagnosis. The aetiology of AD is still largely unknown. Though the disease can occur in middle adult life or even earlier, in the case of AD with early onset, it appears mainly in later life after 65 years of age, usually in the late seventies or thereafter. In cases with early onset, there is a likelihood of a family history of the disease and a rapid deteriorating course marked by multiple disorders of the higher cortical functions. Finally, though some drugs slow down cognitive decline, AD is still at present irreversible.

As AD is related more or less exponentially to age, one can expect a significant increase in the prevalence of the disease, as the population grows older. This assumption is obviously based on the current situation and could change considerably if, for example, new drugs or other treatments could prevent or possibly reverse the disease. In Europe an important study (called Eurodem) conducted under the auspices of the European Commission DG V and co-ordinated by the Department of Epidemiology and Biostatistics of Erasmus University in Rotterdam has brought together the results of ten population-based studies on dementia in older persons (1). Eight countries were involved in this project. Eurodem studies show that women at all ages have a higher prevalence of AD than men. There is a significant increase of the prevalence rate by age for both sexes leading to a rate of slightly over 20% for women and slightly less for men in the age group 90+. The Eurodem study shows rather similar patterns between European countries and it is doubtful that prevalence differs widely between countries and regions if one takes into account the same definition of the disease and the same case ascertainment procedure (2). No differences have neither been found between races in a study using the same assessment criteria (3). Incidence rates by age follow the same pattern as prevalence rates. Once again, the pooled data from the Eurodem studies show that rates for women are

higher than for men and furthermore that female rates increase more sharply by age than they increase for men.

The present research has been conducted in the framework of the Action Programme of the European Commission DG V in favour of persons suffering from Alzheimer's disease. The main objectives of this research were to make an inventory of hospital statistics (from all institutions dealing with mental health problems) on AD collected in the member countries of the European Community, to assess the quality, the coverage, and the comparability of these data, to evaluate the support of the patients with AD, and to study the different diagnostic procedures of AD among the specialised wards (neurology, geriatric, psychiatry, memory clinics). The present paper deals with the first parts of the research project i.e., to assess the levels of hospitalization rates for AD in the countries of the European Union, to compare the procedures of data collection in this field, and to evaluate their quality and comparability. In general, hospital statistics concern cases which have required hospitalizations and very often do not consider hospital outpatients. Therefore, they do not identify all the cases and most significantly will depend on the differences existing between the diagnostic means amongst different hospitals in a country, and on the differences between the health systems of the countries (4). Furthermore, hospitalization rates can be very different from incidence rates, as is the case with AD, due to the fact that many patients suffering from AD are not hospitalized and if they are hospitalized, one does not know if it is a new case of AD.

Materials and methods

In view of identifying available data on AD in the fifteen countries of the European Union, a questionnaire was sent during the first semester of 1998 to all the national institutes of statistics and ministries or national boards of health, taking account of possible regional institutions also. This questionnaire aims at obtaining information on the type of health institutions where AD patients are institutionalized, those which collect data on dementia in a systematic way, the procedures of codification and publication, and the possible collection of associated diagnoses. Information was also asked concerning which characteristics of the patient are collected (e.g. age, sex, place of residence). Data on hospitalization numbers for dementia were provided by the institutions following the types of coding procedures used except for Belgium, Denmark, Finland, France, Italy and Luxembourg.

One point of particular interest is according to which International Classification of Diseases revision (ICD-9 or 10) the data are coded and

if a three, four or five digit code is used. Under ICD-9 (5), the various types of AD can be coded both under the chapter on diseases of the nervous system and the chapter on mental disorders. The latter concerns only dementia in AD. In ICD-9, code 331.0 (diseases of the nervous system) refers to AD without dementia, and code 290.1 (chapter on mental disorders) refers to presenile dementia including dementia in AD. Dementia in AD with an onset after 65 years can be coded under 290.0, 290.2, or 290.3. However, the term Alzheimer's Disease is never used as such. If the 3-digit code 290 is used, vascular dementias are also included under this grouping, but they have a different etiologic origin than AD. In the case of the 3-digit code 331, other degenerative diseases such as Pick or Creutzfeldt-Jacob are also subsumed. In ICD-10 (6), AD is once again included in the chapters on Mental and Behavioural Disorders (F00) and Diseases of the Nervous System (G30). AD can be identified with the help of three characters only (one letter and two digits), the 4-character codes referring to early onset, late onset and atypical or mixed type. AD is now clearly identified as such, a fact which will most probably lead to more precise codification of this disease once ICD-10 will be in general use. Furthermore in ICD-10, the diagnostic criteria for AD are closer to those of DSM-IV (Diagnostic and Statistical Manual – fourth edition), the classification elaborated by the American Psychiatric Association, which is the standard reference for mental disorders (7). In this paper AD is estimated for ICD-9 by regrouping codes 290.0, 290.1, 290.2, 290.3, and 331.0, though as we have seen, some other mental disorders could also be included. For ICD-10, hospitalizations for AD are obtained with F00 only (G30 unavailable) for England, and F00 + G30 for Wales (any mention of the diagnosis).

In order to reduce random fluctuations in the data, the average number of hospitalizations for several years were computed by five year age groups and gender for the periods for which data were available, i.e. Austria 1993-96, England 1992-95, Scotland 1991-96, Northern Ireland 1994-96, Republic of Ireland 1994-97, Netherlands 1994-96, and Sweden 1994-96. Hospitalization rates per year were then computed by dividing the average number of hospitalizations by the mid-period population by sex and by five years of age for each of the countries concerned.

Results

All the countries of the European Union, except Denmark, have answered the questionnaire. Some data for Denmark were however obtained from the literature. As the health services of the United Kingdom are

regionalized, England, Wales, Scotland, and Northern Ireland gave separate answers. In 1998, all European countries have a national systematic registration system of hospital data. These systems are however recent, most dating from the 1960's. The first countries to set up such a system were England and Wales in 1950 and Italy in 1955. The last countries to join the set are France in1996 and Luxembourg in 1997. Public hospitals are required to participate in the system except in the Netherlands, where registration is not compulsory even though the coverage is practically complete since 1985 for general hospitals. Some countries such as Belgium, the Netherlands and the Republic of Ireland have a dual registration system, one for general hospitals and the other for psychiatric hospitals. In Ireland eg., procedures of data collection and coding are different for the general hospitals and psychiatric hospitals. For the former, ICD-9 is used while ICD-10 is in application for the latter. The Netherlands and the Republic of Ireland also collect data from nursing homes. All countries collect data by age and sex of the patient, and by place of residence; some countries also collect data on marital status. Eleven countries out of the fifteen do not distinguish between first hospitalization for a specific disease and re-hospitalization for this same disease. The four other countries (Denmark, Finland, Portugal and Sweden) can distinguish between the two on the basis of the personal identification number. Some countries such as Greece, Italy, and Spain collect the data on the basis of a sample of hospitals or discharges.

Table 1 presents some characteristics of hospital statistics in the European Union countries concerning procedures of collection, codification, and publication of the data. As one sees there is a variety of procedures, codification practices and forms of publication among the various countries. Comparison of hospitalization rates for Alzheimer's disease must therefore take these differences into account. Some countries have furthermore undertaken specific studies linking various registers together. In Finland for example, for the period 1990-1995, personal identity numbers of all patients with dementia diagnosis were gathered from the national discharge registers for health care. All entries of these persons in the discharge registers of 1995 (social welfare and health care) were collected. The registers cover all in-patient care in Finland plus housing services and regular home care services and enable to evaluate the costs of caring for patients with dementia. Furthermore some countries such as Belgium or Sweden are developing specific registration systems for the psychiatric sector. In Sweden, this source deals both with in- and outpatients. In Belgium only in-patients are taken into account and data concerning the evolution of the disease are recorded during the whole of their stay in the hospital.

TABLE 1
Characteristics of hospital statistics in the European Union countries (1/1/1998)

Countries	First year and information system concerned	Data collected	Nb of associated diagnose(s)	Codification	Publication	Information about out-patient
Austria	1989	Public hospitals: all discharges	Nine (not published)	ICD-9 (four digits)	ICD-9 – Krazaf	No
Belgium	1990: *Résumé Clinique Minimum* (RCM) for general hospitals	All discharges in hospitals receiving public funding	RCM: Eight	ICD-9 (five digits)	RCM: Following classification Diagnosis Related Groups (DRG) + 30 most frequent diagnoses. ICD-9 (three digits)	Partially for out-patient surgery
	1996: *Résumé Psychiatrique Minimum* (RPM) for psychiatric sector	Id.	RPM: Seven	DSM-IV		
Denmark	1976: National Register of Hospital Patients					Yes
Finland	1967, modified in 1995	The Care Report system covers all discharges in public and private hospitals, and institutional care. Register of health care services in municipalities.	Two	ICD-10 (five digits)		Yes
France	Before 1996 surveys on hospital morbidity. Since 1996 PMSI *Programme de médicalisation des systèmes d'information*	PMSI: all discharges in short-stay public or private hospitals with public funding	Fifteen, from the year 2000.	ICD-10 (five digits)	Following classification *Groupes homogènes de malades* (similar to DRG)	No
Germany	1993 at federal level. Coverage 99%	All discharges	None	ICD-9 (four digits)	ICD-9 (three digits)	No

TABLE 1 (continued)
Characteristics of hospital statistics in the European Union countries (1/1/1998)

Countries	First year and information system concerned	Data collected	Nb of associated diagnose(s)	Codification	Publication	Information about out-patient
Greece	Not available	All discharges in public hospitals	None	ICD-9 (three digits)	Main diagnoses groups	No
Ireland Rep.	1970: Hospital In-Patient Enquiry	All discharges in public hospitals	Five	ICD-9 (five digits)	Not published	No
	1965: National Psychiatric In-Patient Reporting System	Hospitalizations in psychiatric hospitals: coverage: 96%	One	ICD-10 (four digits)	Main diagnoses groups	No
	1981: Survey of Long Stay Units	Coverage 87% of Long Stay Units	None		Main diagnoses groups	
Italy	*General Hospitals* 1955 – ISTAT *Indagine Campionaria sui dimessi dagli Instituti di Cura*	25% of the discharges in public hospitals during the first seven days of each month	Not available	Not available	Not available	Not available
	1994: Ministry of Health *Schede di Dimissione Ospedaliera*	All discharges during the first seven days of each month	Three	ICD-9	Following classification *Raggrupamenti Omogenei di Diagnosi* (similar to DRG)	No
	Psychiatric Hospitals since 1957: ISTAT	Hospitalizations during the first seven days of each month	None	ICD-9 (four digits)	ICD-9 (four digits)	No
Luxembourg	1997	All discharges	Five	ICD-10	Will be published following three digits	No
Netherlands	1960: *Landlijke Medische Registratie*	Voluntary basis. Since 1985 coverage 99%	Ten	ICD-9 (four digits)	Main diagnoses groups	Yes
	1967: PIGGP	Hospitalizations in psychiatric hospitals. Full coverage is not reached	Two psychiatric diagnoses and two somatic diagnoses.	ICD-9 (four digits)	ICD-9 (four digits)	Yes
	1980: *Verpleeghuis Informatie System*	Nursing Homes coverage 85%	Two	ICD-9 (four digits)	Main diagnoses groups	Yes

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TABLE 1 (continued)
Characteristics of hospital statistics in the European Union countries (1/1/1998)

Countries	First year and information system concerned	Data collected	Nb of associated diagnose(s)	Codification	Publication	Information about out-patient
Portugal	1992	All discharges in public hospitals	Six	ICD-9 (five digits)	Following classification DRG	No
Spain	1977: *Encuesta de Morbilidad Hospitalaria*	Sample: 25% patient discharges in a sample of hospitals	None	ICD-9 (three digits)	Main diagnoses groups	No
United-Kingdom England	1950-1986: Hospital In-Patient Enquiry: general hospitals	10% of all discharges	Not available	Not available	Main diagnoses groups	Yes
	Mental Health Enquiry: psychiatric hospitals	All hospitalizations				
	Since 1987: Hospital Episode Statistics	All discharges in public hospitals	Six	ICD-9 (four digits) ICD-10 since 1995-96	ICD-9 (three digits) ICD-10 (three digits)	No
Northern Ireland	1968: General hospitals (excluding psychiatric sector)	All discharges in public hospitals				
	Mental Health In-patients System: psychiatric sector	Coverage: 95% of the hospitalizations	Five	ICD-9 ICD-10 since 1996-97	Main diagnoses groups Id.	No
Scotland	1961: General hospitals (excluding psychiatric sector)	All discharges in public hospitals	Five	ICD-9 (four digits) ICD-10 (five digits) since 1996-97	Main diagnoses groups	Yes
	1958: psychiatric sector	Id.	Three	Id.	Id.	
Wales	1968 1991: Hospital Episode Statistics for Wales	All discharges in public hospitals	Six	ICD-9 (four digits) ICD-10 since 1995-96	Main diagnoses groups Id.	No

TABLE 1 (continued)
Characteristics of hospital statistics in the European Union countries (1/1/1998)

Countries	First year and information system concerned	Data collected	Nb of associated diagnose(s)	Codification	Publication	Information about out-patient
Sweden	1964: regional 1987: national In-Patient Discharge Registry	All discharges in public hospitals	Five	ICD-9 (four digits, with the fourth digit different from those of ICD-9) ICD-10 (four digits) since 1997	Main diagnoses groups	Not available
	1994: Global Assessment of Psychosocial function	All hospitalizations in the psychiatric sector	Three for hospitalizations in psychiatry	DSMIII-R, DSMIV	Not available	Yes

The data that can be used for statistical aims are discharge diagnoses. To evaluate the incidence of hospitalization for a specific disease, it would be necessary to know if hospitalization for this disease is a new case or a recurrent case. This would give the true number of cases of hospitalization for this disease during a specific year, since repeated hospitalizations of the same patient will overestimate the frequency. Matching over several years would enable identification of the same cases reported several times for recurrent hospitalizations, but except in countries using personal identity numbers linkage using individual characteristics such as name or address will often be unreliable. Sweden and Portugal take only first hospitalization during the year into account, all the other countries consider both first hospitalization and re-hospitalizations. Data for Wales include any mention of the diagnosis. Those for Northern Ireland relate only to the National Mental Health In-Patient System.

In order to compute hospitalization rates for AD, data have to be codified according to ICD-9 with at least four digits or following ICD-10 with three characters. The only countries or regions having provided these data are Austria, England, the Republic of Ireland, Northern Ireland, Netherlands, Scotland, Sweden, and Wales. Figures 1 and 2 present the male and female hospitalization rates for Alzheimer's disease for these
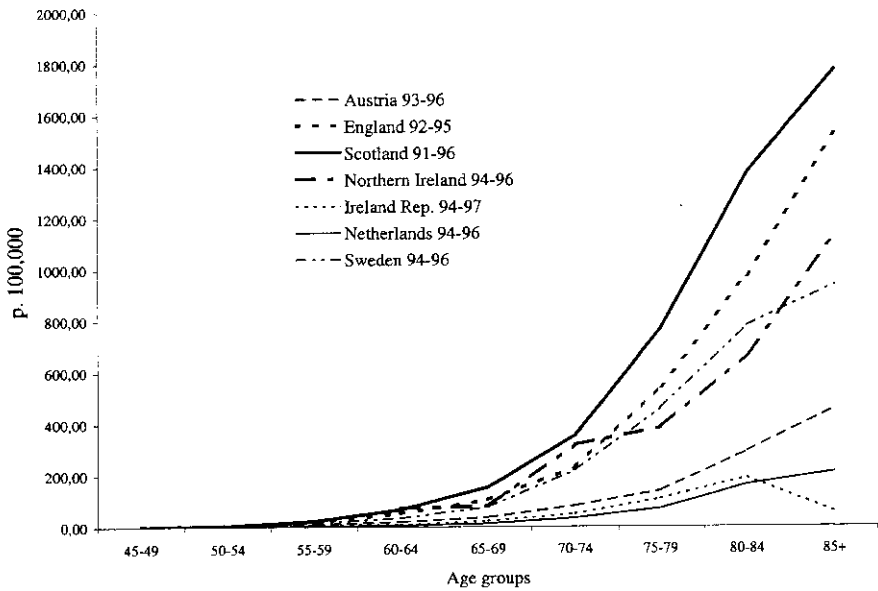
Fig. 1: Males hospitalization rates for Alzheimer's disease in
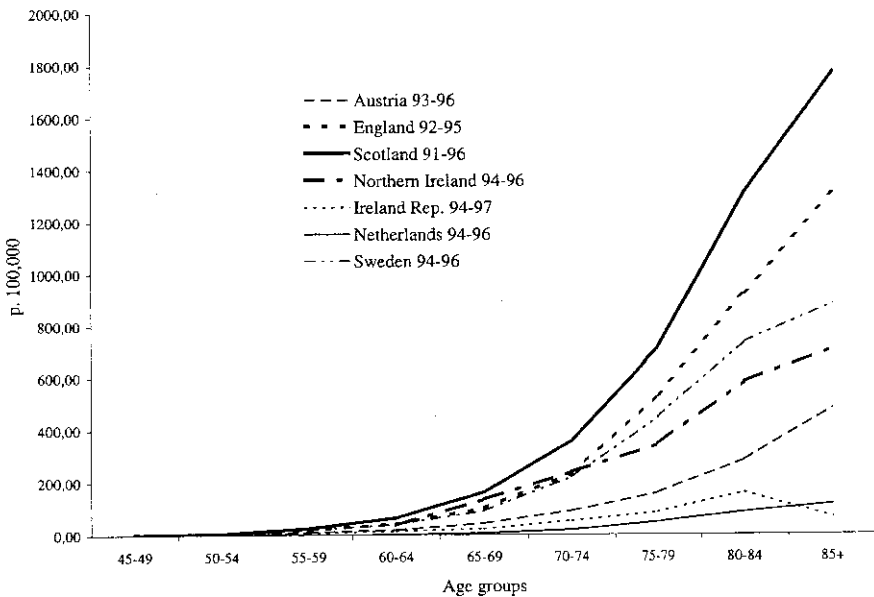various European countries (discharges p. 100,000)

Fig. 2: Females hospitalization rates for Alzheimer's disease in
various European countries (discharges p. 100,000)

areas. Wales has however not been included in the two figures, as the
data we have received do not distinguish between main and associated
diagnoses. Cases where AD appears as associated diagnoses have
been excluded from the data.

As expected, hospitalization rates for AD as main diagnosis increase significantly with age in all the countries concerned, except for the last age group in Ireland where the number of cases is however small. This drop could nevertheless be due to an actual decrease in the recourse to hospitalization by the very old, the most plausible reason being that these persons are already taken care of in other long-stay institutions (8). Moreover, contrary to the results of the Eurodem study which show a much higher incidence for females than for males, hospitalization rates are not very different between males and females. Levels are difficult to compare among countries, as the information systems differ as seen in table 1. One can nevertheless point out the higher rates for England and for Scotland, and especially the low levels of hospitalization for AD in the Netherlands in spite of the excellent coverage of the system.

Comparisons between ICD-9 and ICD-10 can be made for Wales, the only country in the data set including the relevant codes. In this case data concern, as stated above, "any mention of the diagnosis", therefore including associated diagnoses. Figure 3 presents the Welsh hospitalization rates for AD codified according to ICD-9 and ICD-10. One sees that ICD-10 leads to a much lower level of hospitalization rates than ICD-9, due to much stricter criteria in specifying AD. One can also see that hospitalization rates for Wales with ICD-9 are much higher than those for the Netherlands where, for the year 1997, associated diagnoses were also available. Medical practices would therefore seem to differ quite strikingly in this field.

Discussion and conclusion

Hospital statistics obviously only concern cases which have been hospitalized and generally do not consider hospital outpatients. Data on the latter would be useful in order to obtain a better picture of the recourse to hospital care by persons with AD, as most diagnostic means for AD do not require hospitalization. Furthermore, in most countries private hospitals are not included in the database. Therefore hospital statistics do not identify all the cases, and most significantly will depend on the differences existing between the diagnostic means amongst different hospitals in a country and on the differences between the health systems of the countries (diagnostic means in public and private medicine, compulsory consultation of a GP or direct consultation of a specialist). In addition, coding practices may differ between countries and even between hospitals when confronted with cases of co-morbidity or uncertain
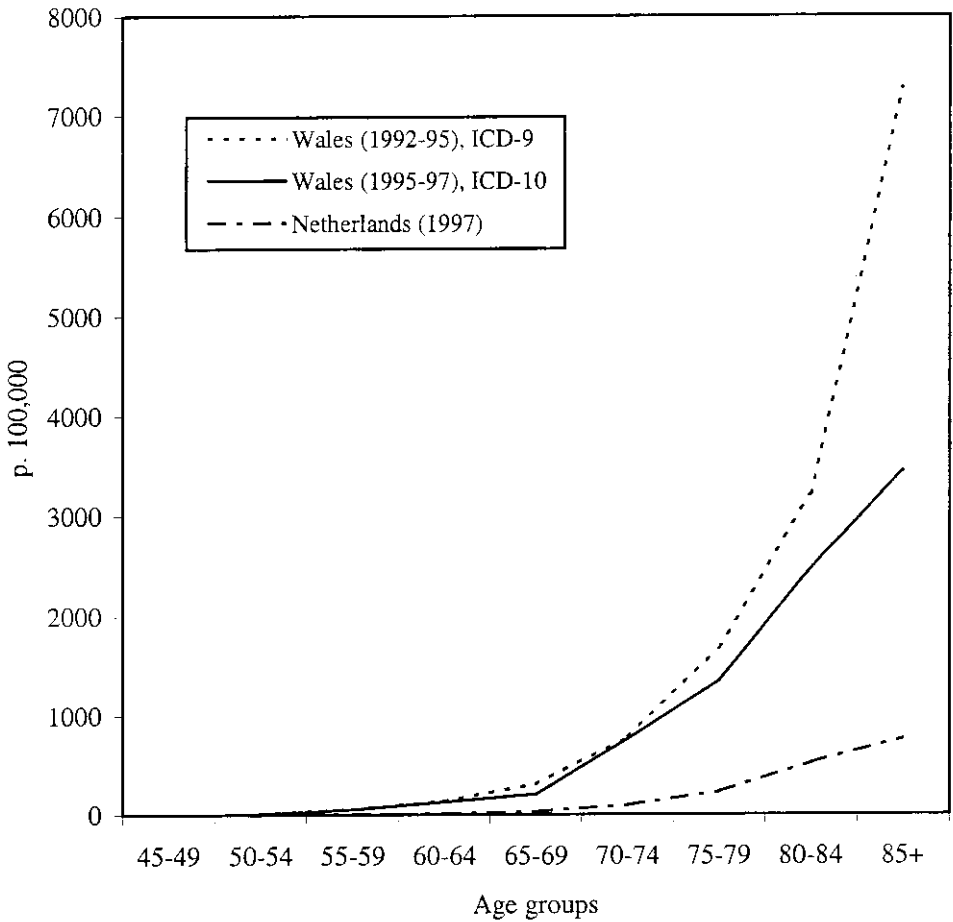
Fig. 3: Hospitalization rates for AD including associated diagnoses codified following
ICD-9 and ICD-10 in Wales and codified according to
ICD-9 in Netherlands (discharges p. 100,000)

cases such as possible AD. Following the recommendations of ICD-10, associated diagnoses should be considered where appropriate for the evaluation of hospitalization rates due to AD.

As stated above, most countries do not distinguish between first hospitalization and re-hospitalization. It is therefore not possible in most cases to evaluate the incidence of hospitalizations due to a specific disease. On the other hand, from an economic viewpoint, one is interested in all hospitalizations; even here however, it would be useful to estimate the number of hospitalizations per person and the person-time spent within the hospital, in order to project future needs in hospital care assuming that caring practices do not change. As is well known, patients with AD are

mainly taken care of by their family or in nursing homes and old people's homes. Hospitalization rates therefore do not reflect the true cost of the disease (9).

It has been pointed out that contrary to the age-specific incidence rates, which are higher for females than for males, hospitalization rates are not very different between males and females. A possible explanation would be the composition of the household. As there are more widows than widowers at a given age, due to a lower female mortality, there are proportionally more males cared for by their wife at home than vice-versa, and therefore more females would be cared for in long-stay institutions than males. In this case, there would be less need for a stay in a hospital for these women, as they are already cared for by their institution, than for males who are taken care of at home by their wife.

To conclude, hospital statistics on AD can presently be collected in all the countries of the European Union, especially now that ICD-10 deals specifically with this disease. We have shown however that coverage of the systems, coding practices, and levels of hospitalization rates differ markedly between the countries. Finally, it would be useful to obtain data on outpatients and data for private hospitals in order to complete the information on hospitalization of AD patients.

Acknowledgements

Résumé

Les procédures de collecte de données relatives à l'hospitalization des personnes souffrant d'une maladie d'Alzheimer (MA) sont comparées entre les différents pays de l'Union européenne. L'information a été obtenue auprès des Instituts de Statistiques et de Santé publique. Elle concerne le type d'institutions de soins recueillant les données d'une manière systématique, les procédures de codification et de publication, la collecte des diagnostics associés et les caractéristiques du patient. La couverture et les pratiques de codification diffèrent fortement entre pays. Quand les données étaient disponibles, les taux d'hospitalization pour la MA ont été calculés. Ces taux augmentent considérablement avec

l'âge et ne diffèrent guère entre les hommes et les femmes. La codification des diagnostics selon la CIM-10 conduit à un niveau d'hospitalization moindre que dans le cas de l'utilisation de la CIM-9. Les données sur les patients soignés en ambulatoire ou provenant de cliniques privées n'existent guère à l'heure actuelle; il serait important cependant d'en prévoir la collecte systématique.

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