EUROCODE:

Report of WP 7 2006

Prevalence of Dementia in Europe.

EUROCODE

Workpackage 7

Prevalence

Aim

The project will gather existing epidemiological studies and analyse the respective merits and shortcomings of the individual studies. Based on the report on these studies, consensual European prevalence rates will be developed that will be acceptable to all partners and used as a "golden standard" within the respective organisations.

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Background

Dementia generally has an insidious onset, progresses slowly over years and death is usually due to intercurrent illness, rather than the disease itself. The resulting impact on quality of life, the social / caregiver burden and healthcare systems is significant. This global burden will rise with increasing longevity. The World Health Organisation (WHO) stated in 1997 "Increased longevity without quality of life is an empty prize, health expectancy is more important than life expectancy"

Currently one of the most significantly changing global demographic factors is the increase of life expectancy. In 1950, life expectancy at birth for a European male was 63.4 years; today it is 70.5 years (United Nations, World Population prospects). In addition European birth rates soared after the Second World War. In 2006 the first of this generation turned 60. This change in birth rate and increasing life expectancy has brought about a rapid demographic change in Europe with an increasing number of people living over the age of 60. For example in Germany the dependency ration (the proportion of people over 65 to those aged 20-64) has hovered around 25% for the last 30 years. It is predicted to reach 50% over the next 30 years. The primary risk factor for the development of dementia is age. The demographic shifts in the EU population significantly increase in the number of people at risk of dementia.

Knowledge about the numbers of individuals affected by dementia is essential. For the research community hypothesis generation is often driven by epidemiological data. At a regional, national and international level strategic planning of health and social policy is dependant on accurate estimation of the size of the problem, and with this comes an ability to estimate the future cost of the disease burden. At an individual level the ability of patient associations to be able to offer evidence based knowledge to patients and caregivers is a minimal expectation.

In 1991 EURODEM (EU funded) based in Erasmus Medical Centre, Rotterdam, published a collaborative study of 12 population based epidemiological studies from 8 countries looking at the prevalence of dementia in Europe. The work was updated in 2000. The articles are highly relevant today but are based on cohorts commenced in the 1980's, and does not include data from Eastern Europe. In addition to the important collaborative prevalence data resulting from this work, the project had huge methodological significance in that the differences in epidemiological methods used and resulting study quality across Europe was discussed and minimum standards for future work were proposed. The quality of population based epidemiological studies performed since this time have enormously benefitted from EURODEM discussions.

Since the EURODEM publications world prevalence rates for dementia have been estimated using entirely different methodology. DELPHI consensus methods were used to review global prevalence and estimates for prevalence for each continent were published in 2005. "Delphi consensus is a method for making estimates where an evidence base exists but data are incomplete, scanty or otherwise imperfect. The essence of the method is deriving quantitative estimates through the qualitative assessment of research evidence. It is an interactive process of consensus. Experts first make estimates independently, which are then aggregated and fed back anonymously so that they may review them in the light of group-wide choices." This project considered prevalence rates for all continents. That for Europe was based on reviewing evidence from just 4 European Studies of prevalence and did not provide age and sex specific rates.

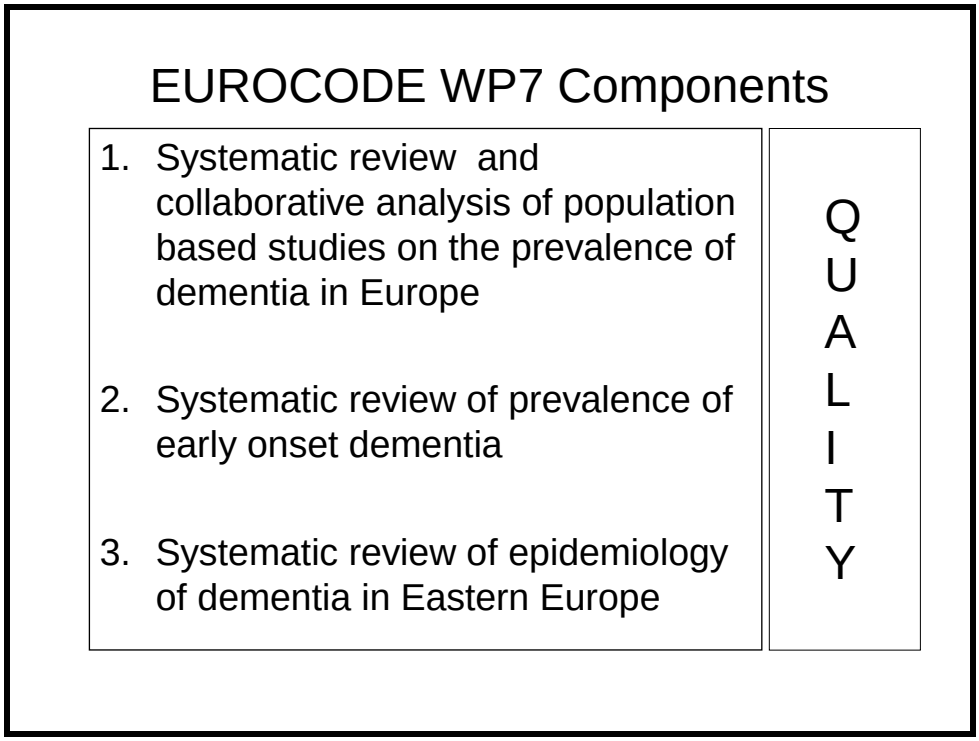
This project, by means of an extensive literature search using Cochrane review methodologies, has compiled a database of all European epidemiological studies in this field up to the present date.

Systematic reviews of 1) prevalence of dementia, 2) prevalence of early onset dementia and 3) prevalence of Dementia in Eastern Europe have been performed.

Data from high quality studies performed in the last 20 years looking at dementia prevalence have been pooled in a collaborative analysis. Age and sex specific prevalence rates have been calculated using this prevalence data. An outline of the components of the project are presented in Fig. 1

Methods and results of each of these component parts will be described separately in the report.

Figure 1



1) Systematic review and collaborative analysis:

Prevalence of dementia in Europe

Methods

A Systematic review of papers reporting on the prevalence of dementia was performed. Using a Medline and Embase search we found a number of studies using the search terms “Dementia / Prevalence / Incidence / Epidemiology” or “Alzheimer’s Disease / Vascular dementia, Lewy-body disease/ Fronto-temporal dementia/ Incidence / Prevalence / Epidemiology. This was followed by hand searching these papers. A database of studies was compiled and those fulfilling predetermined quality criteria were invited to submit data for the collaborative analysis

Collaborative analysis

Inclusion criteria (Table 1) for involvement in the collaborative analysis were decided by the members of the EUROCODE prevalence working group. These were developed by consensual opinion looking at all methodological domains of this type of epidemiological study. Criteria were aimed to identify those studies of highest quality. Studies fulfilling criteria were invited to participate in the collaborative analysis. Age (by 5 year age group from 50 to >95years) and sex specific raw prevalence case numbers and underlying population were collected from all groups agreeing to participate in the collaborative analysis.

Table 1

Inclusion Criteria:-
1. Community based study
2. Minimum sample size 300
3. Study survey date including 1990 or thereafter.
4. Use of standardized diagnostic criteria
5. Participation rate over 50%
6. Available raw prevalence data

Analysis

Age (5 year age range) and sex specific raw data from participating studies was included in the analysis. Data above 95 years was combined. Below this age raw data that could not be presented in 5 year age groups was excluded from the analysis. Age and sex specific prevalence's were calculated using the total number of prevalence cases from all studies as the numerator and total population examined as the denominator. In this way weighting was achieved by each study's sample size.

Results

A total of 194 articles were identified from the literature search. 31 studies were identified as possible for inclusion in collaborative analysis and they were invited to submit data. Raw data was obtained from 17 studies and used in the collaborative analysis of dementia prevalence rates in Europe. Table 2 outlines the 31 studies identified for participation and if not finally included the reason for non inclusion in yellow.

Table 2

Author	Year of publication	Year of Survey	Country	Reason for exclusion
Skoog	1993	1986-1987	Sweden	Too early
Roelands	1994	1990	Belgium	Raw data not available
Lobo	1995	1988-89	Spain	Too early
Manubens	1995	1991	Spain	
Pouza	1995		Spain	Too small
Ott	1995	1990-93	Netherlands	
Fichter	1995	1990	Germany	Raw data not available
Pi	1996	1992	Spain	Raw data not available
Prencipe	1996	1992-93	Italy	
Andersen	1997	1994	Denmark	
Ferini-Strambi	1997	1992	Italy	
Obadia	1997	1991	France	Raw data not available
Boersma	1998	1991-92	Netherlands	Raw data not available
Azzimondi	1998	?	Italy	
MRC FCAS (Liverpool)	1998	1989-91	UK	Too early
MRC FCAS (All other centres)	1998	1991-92	UK	Raw data not available
Strauss	1999	1992-1993	Sweden	
Gabryelewicz	1999	1996	Poland	
Vilalta-Franch	2000	1990	Spain	
Cristina S	2001	1992-93	Italy	Low participation
Kurz	2001	?	Belgium	Not population based
Riedel-Heller	2001	1997-1998	Germany	
Ravaglia	2002	1999-2000	Italy	
Stevens	2002	1996-2000	England	Raw data not available
Gostynski	2002	1995-1996	Switzerland	
Borjesson-hanson	2004	1998	Sweden	
Tognoni	2005	2000	Italy	
De Ronchi	2005	1991-1992	Italy	
Helmer	2006	1998-99	France	
Bdzan	2007	2002-2005	Poland	
Lobo A	2007	1994-96	Spain	Raw data not available
Gascon-Bayarri	2007	2002	Spain	

Prevalence rates from individual studies.

Table 3 shows the basic characteristics of each study included in the collaborative analysis with differences in geographical region, study size and age range of population evaluated.

Table 3

Author	Country	Number of participants	Age range	Prevalence of dementia (%)
Gabryelewicz	Poland	893	65-84	5.7
Ravaglia	Italy	1016	≥65	5.9
Tognoni	Italy	1600	≥65	6.2
Ott	Netherlands	7528	>55	6.3
De Ronchi	Italy	7930	≥61	6.5
Bdzan	Poland	1000	≥60	6.7
Andersen	Denmark	3346	65-84	7.1
Prencipe	Italy	968	≥65	8
Gascon-Bayarri	Spain	1754	≥70	9.4
Ferini-Strambi	Italy	673	≥60	9.8
Gostynski	Switzerland	465	≥65	10.1
Strauss	Sweden	1424	77-84	13
Vilalta-Franch	Spain	1460	≥70	16.3
Manubens	Spain	1127	>70	17.2
Riedel-Heller	Germany	1265	≥75	17.4
Helmer	France	1461	≥75	17.8
Azzimondi	Italy	727	>74	21.9

Prevalence rates from collaborative analysis.

Table 4 shows **male** age and sex specific prevalence rates of dementia

Table 4

Male Age Range	Prevalence
60-64	0.2
65-69	1.8
70-74	3.2
75-79	7.0
80-84	14.5
85-89	20.9
90-94	29.2
>95	32.4

Table 5 shows **female** age and sex specific prevalence of dementia

Table 5

Female Age Range	Prevalence
60-64	0.9
65-69	1.4
70-74	3.8
75-79	7.6
80-84	16.4
85-89	28.5
90-94	44.4
>95	48.8

Total age specific prevalence rates were calculated by pooling data on prevalence case numbers and underlying population for males and females in each 5 year age range. Table 6 shows these rates

Table 6

Total Population Age Range	Prevalence
60-64	0.6
65-69	1.6
70-74	3.5
75-79	7.4
80-84	15.7
85-89	26.2
90-94	41.0
>95	46.3

Comparison with previous data.

Figures 1 and 2 show graphically the comparison of the current data with that from the EURODEM project.

Figure 1

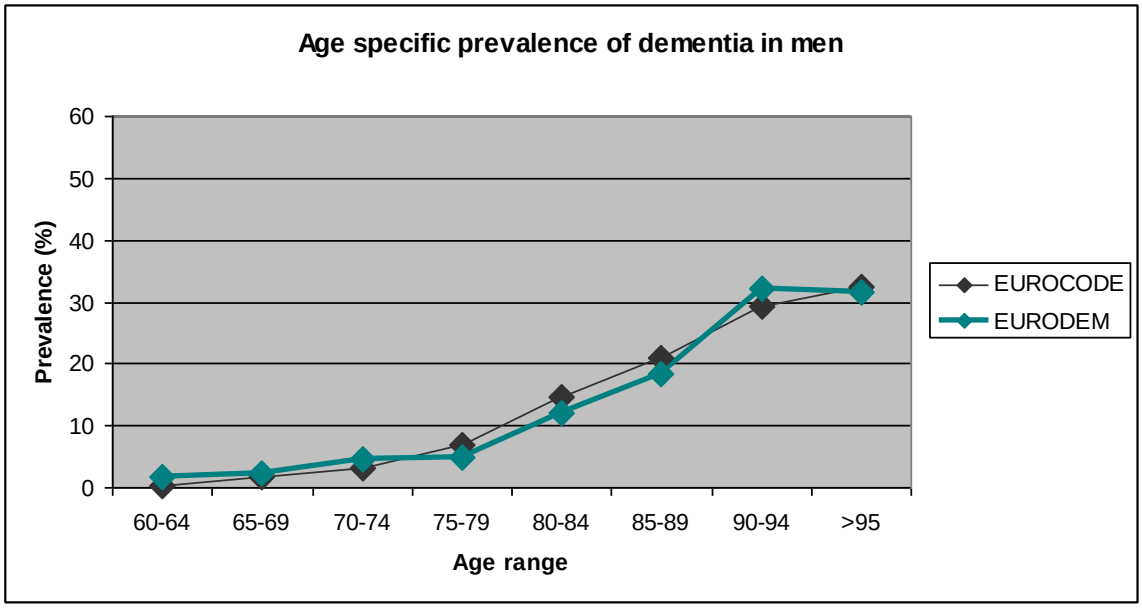
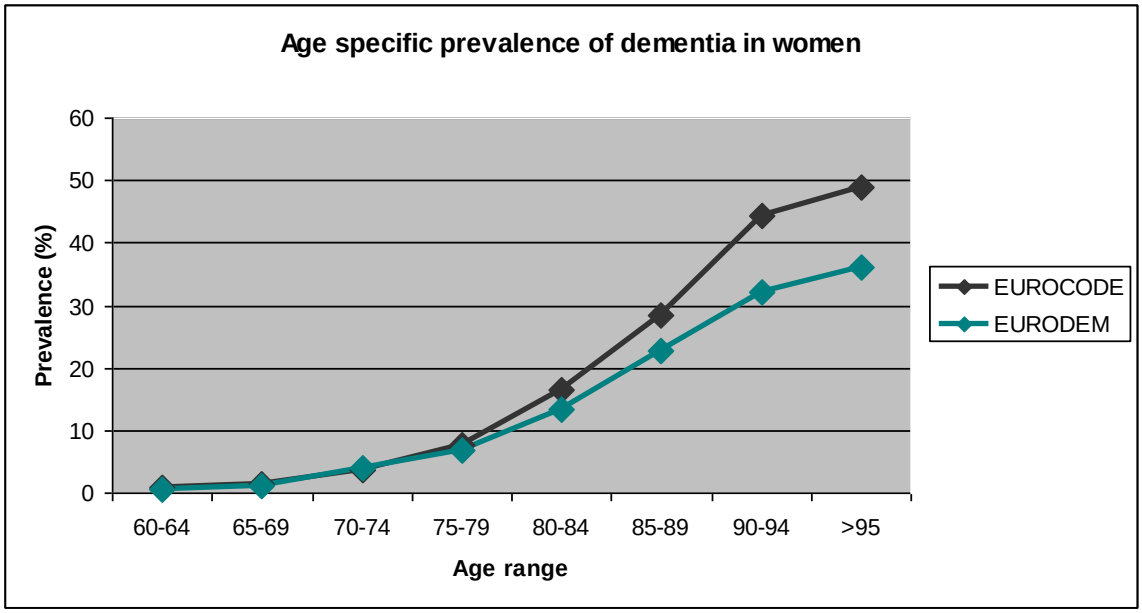


Figure 2



Discussion

From the current collaborative analysis it appears that for the majority of age groups dementia prevalence has not changed significantly over the last few decades despite the current analyses using completely new data from that included in EURODEM. Within the oldest old however dementia prevalence is higher in females and this level of prevalence has not been previously documented. This finding may be as a result of a higher proportion of studies reporting dementia prevalence in the older age ranges over the last 2 decades and probably reflects a true rate in this previously under reported population.

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2) Systematic review:

Prevalence of early onset dementia

Introduction

Dementia is often thought of as a condition of old age and although most cases are found in the elderly a significant number of people develop symptoms of dementia at a younger age. Patients with onset of symptoms below a certain age (usually set arbitrarily at 65) are said to suffer from "early onset dementia" or "presenile dementia". The causes and classification of dementia in this age group are the same as in the more elderly population in that Alzheimer's disease, vascular dementia, Lewy body dementia and frontotemporal dementia can all be recognised.

Study Design

We summarise the findings of studies reporting the prevalence of early onset dementia. We included studies that had determined prevalence rates of dementia in patients less than 65 years of age. Using a Medline and Embase search we found a number of studies using the search terms "Dementia/Prevalence/Epidemiology" or "Early onset dementia/Incidence/Prevalence/Epidemiology." We followed this with a hand search of the references of these studies as well as any knowledge of any studies by the authors. To be included in the review studies needed to specify prevalence of dementia in subjects aged 65 or younger either looking specifically at this younger age group or as a easily identifiable subgroup of a larger study population. Papers that included the younger age groups but could not be easily determined from older ages were excluded. Those reporting only on incidence were also excluded. The initial database search produced 9 references, 5 of which were included in the review. A further 5 papers were identified by hand-searching the references of publications in the initial database search.

Results

The methodology and geography of the papers found reporting prevalence are summarised in table 1. Their key findings are summarised in tables 2a-2d which also give a breakdown of the prevalence in different “pre-senile” age groups, of different sub-types of dementia and any gender differences where given.

Table 1: Methods of studies giving prevalence of early onset dementia

Lead Author	Year of publication	Location	Study design	Case ascertainment	Types of dementia studied	Diagnostic criteria
Ott[6]	1995	Rotterdam, Netherlands	Field study/ Population Based	All residents in study area invited for assessment.	All types of dementia	DSM –III-R (all dementia and vascular), NINCDS-ADRDA (AD)
Sulkava[4]	1985	40 study areas throughout Finland		Interview and examination of representative sample of population.	Primary, Vascular, Secondary.	DSM-III
Harvey[1]	2003	London, UK	Cross-sectional/ Registry	Identified by GPs, psychiatrists, neurologists, geriatrician, general physicians, hospital information systems and case registers	Alzheimer's, vascular, Lewy body, fronto-temporal, alcohol and others.	See footnote A
Rosso[7]	2003	Netherlands		Postal enquiry to neuro and psychiatric hospital services, physicians in psychogeriatric hospitals and nursing homes. Databases of medical centres specialising in dementia	Fronto-temporal	Lund and Manchester
Ratnavalli[2]	2002	Cambridgeshire, UK		Primary – database from memory, early dementia and Huntington's disease clinics. Secondary – inpatient electronic records, 250 GPs, 7 geriatric psychiatrists, clinical psychology services, comm. resource teams and nursing homes	Fronto-temporal, Alzheimers, PSP, Lewy body, vascular, alcoholic, PD, multisystem atrophy	DSM-III
Campion[8]	1999	Rouen, France		GP, neurology, psychiatry referrals to Department of Neurology	AD	NINCDS-ADRDA
Kokmen[10]	1989	Rochester, Minnesota		Computerised diagnostic and surgical procedural indexes at Mayo Clinic and complementary centralised diagnostic index from other sources of healthcare	"All dementia" and Alzheimer's dementia	DSM-III (for dementia) NINCDS-ADRDA for Alzheimer's dementia
Andreasen[5]	1999	Pitea River Valley, Sweden	Prospective study/	Attendance at neuro-geriatric department	AD, Vascular, "others"	NINCDS-ADRDA (for AD) and NINDS-

			Registry			ARIEN (for Vascular), DSM-III (others)
Newens[3]	1993	Northern Health Region, England	Retrospective / Registry	Computer codings for admissions to hospital, patients referred for CT scan querying dementing process, questionnaires to day hospital, social services, private nursing homes.;	Alzheimer's	DSM-III-R
Rocca[9]	1990	Appignano, Italy		Complete enumeration from registry office list	All types of dementia	DSM-III

A Known disease specific genetic mutation, neuropathological results from cerebral biopsy, or autopsy (top level diagnosis).
NINCDS/ADRDA criteria for Alzheimers, NINDS/AIREN criteria for vascular dementia, Lund and Manchester criteria for Lewy body and frontotemporal dementia, DSM-IV for alcohol related dementia (level 2 diagnosis).
DSM-IV criteria but not for one particular category (level 3).

Table 2a: Results summary of studies giving prevalence of early onset dementia

Lead Author	Number of cases	Types of study (Field or registry)	Prevalence (per 100,000 of population) of **Dementia (all)** (Age range in brackets)	Gender differences	Age Specific Incidences (per 100,000 of population)						
					30-34	35-39	40-44	45-49	50-54	55-59	60-64
Ott[6]	11	Field	420 (55-64)	No significant difference						423	418
Sulkava[4]	16	Field	260 (30-64)	No comment made							
Harvey[1]	185	Cross-sectional/Registry	54 (30-64)	Male > Female but not significant	12.7	8.0	15.5	33.0	62.5	152.1	166.3
Ratnavalli[2]	59	Cross-sectional/Registry	81 (45-64)	Significant male preponderance for FTD but not other types							
Kokmen[10]	10	Cross-sectional/Registry	113 (45-64)	More female cases but not significant				77	40	86	249
Andreasen[5]	8	Prospective/Registry	38 (40-64)	No comment							
Rocca[9]		Registry	90 (60-64)	No comment							90

Table 2b: Results summary of studies giving prevalence of early onset Alzheimer's dementia

Lead Author	Number of cases	Types of study (Field or registry)	Prevalence (per 100,000 of population) of **Dementia (Alzheimer's type)** (Age range in brackets)	Gender differences	Age Specific Incidences						
					30-34	35-39	40-44	45-49	50-54	55-59	60-64
Ott[6]	4	Field	200 (55-64)	No significant							
Harvey[1]	42	Cross-sectional/Registry	17.4 (30-64)	No comment			2.6	6.0	16.4	50.7	77.3
Ratnavalli[2]	11	Cross-sectional/Registry	51 (45-64)	No significant gender differences							
Campion[8]	39	Cross-sectional/Registry	41.2	No comment							
Kokmen[10]	3	Cross-sectional/Registry	68 (55-64)	All 3 cases female but not significant						86	50
Andreasen[5]	6	Prospective/Registry	28 (40-64)	No comment							
Newens[3]	227 (195 identified, 32 estimated	Prospective/Registry	34.6 (45-64)	No significant gender differences				2.4	11.8	35.6	87.3

Table 2c: Results summary of studies giving prevalence of early onset Fronto-temporal dementia

Lead Author	Number of cases	Types of study (Field or registry)	Prevalence (per 100,000 of population) of **Fronto-temporal Dementia** (Age range in brackets)	Gender differences	Age Specific Incidences						
					30-34	35-39	40-44	45-49	50-54	55-59	60-64
Harvey[1]	18	Registry	15.4 (45-64)	No comment				12.0	3.3	25.4	23.2
Rosso[7]	31	Registry	4.0 (45-64)	No comment	0.2		1.2		3.6		
Ratnavalli[2]	11	Registry	15.1 (45-64)	Male:female =4:1 (?significant)							

Table 2d: Results summary of studies giving prevalence of early onset vascular dementia

Lead Author	Number of cases	Types of study (Field or registry)	Prevalence (per 100,000 of population) of **Vascular Dementia** (Age range in brackets)	Gender differences	Age Specific Incidences (where given)						
					30-34	35-39	40-44	45-49	50-54	55-59	60-64
Ott[6]	5	Field	200 (55-64)	No significant difference							
Sulkava[4]	5	Field	0.8 (30-64)	All male but no significance as small number							
Harvey[1]	21	Registry	17.9 (45-64)	No comment					6.6	32.6	38.7
Ratnavalli[2]	6	Registry	8.2 (45-64)	No significant difference							
Andreasen[5]	1	Registry	3 (40-64)	No comment							

Study types, geography and methods

Most of the studies we found that reported on prevalence were performed in Western Europe with a spread between the UK (3 papers)[1,2,3], Scandinavia (2)[4,5] and mainland Europe (3).[6,7,8,9] One paper reported on a study in Rochester, Minnesota.[10]

There was heterogeneity in both study design and in how cases were identified. In the case of rare diseases the usual methods of the field study rapidly reach their limits, since even expensive examinations of extensive samples of the population permit only unreliable frequency estimates due to the low number of illness cases which can be identified in the process. Thus in the three largest prevalence studies with a total of more than 13,000 persons under 65, for example, only a total of 29 dementing illnesses could be diagnosed, among them 8 cases of primary degenerative dementia.[4,6,9] In order nevertheless to be able to estimate the illness burden, in countries with well developed care systems one resorts to identifying rare illnesses through contact with therapy centres. These can be termed registry studies. Contrary to the cases of late life, where frequently no clinical diagnosis is made and medical care of the demented is restricted to that of the GP, this appears to be a suitable method for the investigation of early onset dementia, since almost all afflicted are diagnosed at some time or other in the course of the illness by a specialist and avail themselves of the services of psychiatrists/neurologists, outpatient departments or specialised hospitals for diagnosis and treatment. Thus five of the studies were cross-sectional studies [1,2,7,8,10] and relied on various computer databases and coding systems to identify the majority of cases. Some of them went further by enquiring to a variety of sources in the community (such as GPs, nursing homes, CPNs, clinical psychologists and social services departments) that may be involved with and be aware of patients with dementia to identify them to the study groups. The Pitea Valley study recruited cases prospectively as they attended neurology clinics[5] and Newen et al's

study in Northern England retrospectively reviewed case notes of patients who had had a diagnosis of dementia queried.[3]

Types of dementia

The majority of the papers looked at all cases of dementia whatever the exact aetiology or classification although many did give a breakdown of the prevalence of different subgroups of dementia. One study looked only at Alzheimer's dementia[8] and another looked purely at fronto-temporal dementia.[7] Four of the papers we found were looking specifically for cases of dementia in people aged less than 65,[1,2,3,8] whereas the remainder included people of all ages but included subgroup analyses allowing calculation of prevalence for those with "presenile" disease.[4,5,6,7,9,10] In terms of definition of "presenile" this varied between papers. Most used a cut off of 65 years with either onset or diagnosis before this age required to be included. Campion's study used a cut-off of 61 years.[8]

Results of Studies

The studies' differing designs and breakdown of different dementia sub-types makes direct comparison difficult. Looking firstly at "all dementia" prevalence ranges from 38 to 420 per 100,000 of the population. This variation is likely to be due to the differing mix of dementia types and the relatively small number of cases which can skew results and give broad confidence intervals as discussed above. The higher figure of 420 comes from a paper where the age range was narrower (55-64) thus excluding younger age groups with lower prevalence which would otherwise skew the results.[6] Harvey's paper gave a breakdown of prevalence in different age categories below the age of 65 that indicated a rise in prevalence as age approaches 65.[1] This is to be expected and this rising prevalence is likely to form a continuum with prevalence figures in "senile" dementia of onset after 65 years. It therefore follows that if

you look at just the upper end of the pre-senile age range, as did Ott and colleagues, you will calculate a higher prevalence as you are only looking at the upper end of a skewed population and excluding a younger susceptible population with a lower prevalence.[6] It is therefore unhelpful to compare this figure directly with those from other studies with a larger age range.

Alzheimer's disease prevalence ranges from 15.1 to 153 per 100,000 of the population although the higher figure comes from a study with only 4 prevalent cases so is subject to inaccuracies in estimates of prevalence as discussed above.[6] Again those papers that included a slightly broader age range for pre-senile dementia quoted lower prevalences due to the effect of skewing by including younger age groups.

Those studies that identified fronto-temporal dementia gave figures ranging from 4.0 (in the study looking purely at FTD)[7] to 15.4 per 100,000.[1]

Five of the eight papers commented on difference in prevalence rates between the genders. Ratnavelli and colleagues found a male preponderance in the incidence of FTD but not other dementia subtypes[2] and Campion found Alzheimer's disease prevalence was higher in women.[8] Harvey et al found a slight but non-significant excess in cases in men compared to women.[1] The other three studies that commented on this found no significant gender differences.[3,6,10] The Rochester study found all cases of presenile Alzheimer's disease were in women but as the total number was only three this difference is unlikely to be statistically significant.[10]

Discussion of study quality

There was great variation in the type of population included in addition to the way they were sampled. Only two studies were "national" in that they sampled people throughout the countries of Finland and The Netherlands.[4,7] The Finnish study used a sample of the population distributed throughout 40 areas of the country that was specifically selected to represent the Finnish population aged over 30. The Dutch study used the population of the Netherlands as a whole. All the other studies were performed in either a particular city or region within a country. It could be hypothesised that the "sub-national" studies may be less likely to represent the population of a country as a whole as they will not take into account regional variations. However as the case numbers are small any differences are unlikely to be significant so the sample size and methods are more likely to have a greater influence on the quality of the results. Most of the studies included both rural and urban populations although four were mainly urban based.[1,6,8,10] None of the studies stated they excluded subjects in institutions although many made no mention of this factor.

In terms of the sample size, two studies did not state this number.[3,7] Of the others the population eligible for inclusion ranged from 8000 to 426,710 in the Finnish and Rouen studies respectively.[4,8] However it should be noted that the figure quoted for the Rouen study is the entire population of all ages, many of whom would not be "at risk" of dementia, whereas the Finnish study limited itself to those aged 30 or over. In the two field studies the response rates were 97% and 78% respectively for the Finnish and Dutch studies respectively which would normally be expected to give reasonably representative results.[4,6]

Methods of case ascertainment varied between studies. Two of the three field studies used screening methods involving tests of memory and intellectual function at first to identify those who may have dementia. They were then assessed further by a combination of

neuropsychological testing, neuroimaging, blood tests and functional assessment to determine firm cases. As with any screening test sensitivity is unlikely to be 100% so a few cases may have been missed. However the cross-sectional/registry based studies rely on the fact that subjects have been in contact with either medical or care giving organisations meaning cases may have been missed if they had not yet come to the attention of such services. As stated above, this is less likely with younger populations than older ones as people are more likely to seek assistance and investigation for symptoms of dementia if it occurs in a younger patient rather than an older patient in whom many may just view it as part of the ageing process. However it is likely that sensitivity for case identification is greater in the field studies which most likely reflects the large step up in quoted prevalence figures in these two studies compared to the registry based studies. This also suggests there may be a large number of cases that are not coming to the attention of the medical/caregiving services.

Discussion

Epidemiological data for prevalence rates for early onset dementia is sparse. The majority of studies are European. Early onset dementia remains a rare condition with relatively low case numbers. The wide variation in rates across studies may be due to differing study design (case attainment, and diagnostic criteria) in addition to the sparsity of prevalence cases, which necessitates the study of vast underlying populations in order to reach an accurate true estimation.

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3) Systematic review:

Epidemiology of dementia in Eastern Europe

Background

One of the EURODEM goals was to harmonize the protocols used in their newly initiated, population-based follow-up studies. Unfortunately EURODEM did not include data from Middle and Eastern Europe. As a consequence, it is unknown what proportion of the total European population is affected by and suffer from dementia and whether these estimates differ by region, country and culture. Due to the lack of previous systematic inquiries in this domain, it is also unknown in which countries and for what types of dementia epidemiological studies have ever been conducted and to what degree these studies have come to similar results and conclusions. Acknowledging the pressing need for such data, we conducted a systematic analysis of all available epidemiological studies conducted in Middle and Eastern European countries.

METHODS

We adopted a stepwise multimethod study approach consisting of iterative literature searches for epidemiological publications and subsequent data analyses of published material, reanalyses of existing accessible epidemiological data sets and expert inquiries in Eastern and Middle European countries, such as: Albania, Belarus, Bulgaria, Croatia, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Montenegro, Poland, Republic of Moldavia, Romania, Russia, Serbia, Slovakia, Slovenia, Yugoslavia, Ukraine.

We conducted a literature search in scientific databases, conference proceedings, PhD theses, family associations, partner associations, funding organizations for original research articles published between 1990 and 2006. Systematic computer-assisted searches used the keywords: “dementia”, “Alzheimer”, “cognitive impairment”, „incidence”, “prevalence”, “epidemiology” in combination with the name of the relevant countries or “Europe” in English and Polish language. We supplemented the literature search with a review of the references in the articles that were identified during the initial search.

During the search process, we personally contacted numerous European experts or expert groups involved in dementia research from the chosen countries). These contacts were meant to ensure that no study was missed as well as to clarify whether significant information might be obtained by using unpublished data from ongoing or unpublished surveys. However despite considerable attempts we failed to reach experts from the following countries: Albania, Belarus, Bulgaria, Croatia, Hungary, Latvia, Lithuania, Romania, Russia, Serbia, Slovakia, Slovenia.

We excluded the articles that were primarily concerned with subcortical dementias (e.g. due to Huntington disease, Parkinson's disease, AIDS, hypothyroidism, vitamin deficiency). Additionally we didn't take under consideration data from population registers, because of the extremely high variability in diagnostic standards and reporting conventions of the register information.

RESULTS

Country-specific population based studies concerning prevalence of dementia meeting the inclusion criteria of our review are listed in the Table 1 along with a core reference publication for each study listed.. We were able to find 8 publications – 5 studies were carried out in Poland, two in Russia and one in Albania. Sample sizes vary considerably between studies (from *N* = 100 to N > 7417 subjects), as do the age ranges (from >45 to >65 yr). There is also a considerable variation with regard to the spectrum of diagnoses covered in each study (Alzheimer dementia, vascular dementia, mixed dementia, secondary dementia). Most of the studies described are two-step studies with a screening procedure including most frequently MMSE, followed by a diagnostic examination for screen positives. There are also two studies – from Poland and from Estonia - which present only data from MMSE examination (Pajak *et al.*, 1998; Saks *et al.*, 2001).

Several studies were conducted assessing the prevalence dementia in special populations, e.g. among people from departments of internal medicine (Linka *et al.*, 2000;

Klich-Raczka *et al.*, 2006), residential homes (Vincze *et al.*, 2007), neurological units (Klimkowicz *et al.*, 2002; Klimkowicz-Mrowiec *et al.*, 2006) and memory clinics (Sobow *et al.*, 2006). Most of the studies were cross-sectional and two of them were cohort studies (Klimkowicz-Mrowiec *et al.*, 2006; Vincze *et al.*, 2007). MMSE was the most widely used screening tool, followed by diagnosis according to DSM-III-R, DSM-IV, ICD-10 and NNCDS-ARDA criteria. The considerable heterogeneity of populations in which cognitive impairments were assessed and evaluated in the reviewed studies, as well as the great variety of conventions used to report findings, do not allow for joint analyses across studies of aggregated prevalences.

Table 1. Population-based studies on prevalence of cognitive disorders and dementia

Country (place)	**Reference**	**Size of popula-tion sampled**	**Age range**	**Diagnostic procedure**	**Overall all dementia types (M- males F - females)**	**Alzheimer (M-males F-females)**	**Vascular (M- males F - females)**	**Other types of dementia (M- males F - females)**
Poland (Warsaw district Mokotow)	(Gabryelewicz, 1999)	893	65-84	MMSE CAMDEX	7,8%	2,3%	2,7%	Mixed 0,5% Secondary 0,2%
Poland (District Świebodzin)	(Rossa, 1997)	7,417	>=45	MMSE, MSQ, SPMSQ	M: 0,98% F:2,56% Total:3,57%	M: 0,23% F: 1,17%	M: 0,51% F: 1,01%	Mixed M: 0,08% F: 0,12% Other M: 0,16% F: 0,28%
Poland (Town and commune Steszew)	(Wender *et al.*, 1990)	1,000	>=45	neurological and psychological examination	-	1,1% In the age group >65: 10,06%.	`-	-
Poland (rural area near Gdańsk communes: Pruszcz gdański, Trąbki Wielkie and Pszczółki)	(Bidzan and Turczynski, 2005)	1,000	>60	MMSE, ICD-10	M: 3,0% F:8,8% Total:6,7%	M: 1,1% F:4,0%	M: 1,9% F:3,5%	-

Poland (Warsaw)	(Parnowski *et al.*, 1993)	100	>65	MMSE IMC	1,1%	-	-	-
Albania (from the municipal registers of Tirana City)	(Kruja, 2002)	3,521	>60	MMSE ICD-10	M: 4,83% F:11,45% Total:7,75%	-	-	-
Russia	(Sternberg and Gawrilowa, 1978)	-	>60		3,6%	-	-	-
Russia	(Gavrilova *et al.*, 1987)	-	>=60		moderate and severe dementia 4.0% (M:4.1% F: 4%) mild dementia 1.5%	-	-	-
Serbia (data from 16 public health centers)	(Stefanova *et al.*, 2004)	1,000	-	ICD-10	M: 2,8% F: 3,9% Total: 6,7%	-	-	-
Estonia	(Saks *et al.*, 2001)	1,000	>=65	MMSE	Cognitive disorders 23,1%			
Poland (rural province Tarnobrzeg Voivodship)	(Pajak *et al.*, 1998)	943	65-78	MMSE	About 50% had cognitive impairment (MMSE=<25), About 15% had severe cognitive impairment (MMSE=<21) with changes in the brain white matter confirmed by MRI.			

DISCUSSION

Eastern and Middle Europe consists of many countries from different language areas, each of which with different sociodemographic and socioeconomic characteristics, different cultural, legal, social and health care system-related traditions and different psychopathological traditions. All of these factors have been shown to complicate both the conduct of studies as well as interpretations of findings. Unlike the long US tradition of fairly regular, large-scale community and general population studies with uniform methods and designs, there is no such tradition yet in the Europe. During our search, we were able to find few regional and country-specific epidemiological studies of various kinds (population-based studies, cohort studies, cross-sectional studies, community studies) and conducted on different restricted population groups of patients (from neurological units, out-patients units, residential homes). No studies were identified from most of the countries taken under consideration and the ones we found were characterized by an immense diversity with a considerable degree of clinical and methodological variations. The few studies that there are suggest prevalence rates of dementia in Eastern Europe similar to those in Western Europe.

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