Cohort Profile

Cohort Profile: The Health and Memory Study (HMS): a dementia cohort linked to the HUNT study in Norway

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Abstract

The aim of the Health and Memory Study (HMS) of Nord-Trøndelag, Norway, was primarily to establish a database suitable as basis for a large number of studies on dementia. Data from the HMS study were collected via questionnaires and examinations during the period from 1995 to 2011. The dementia panel consists of 620 participants residing in nursing homes and 920 participants referred to memory clinics of Nord-Trøndelag. Data from this dementia panel may be linked to the Nord-Trøndelag Health Study (the HUNT study), three large population based health surveys that took place in 1984–86 (HUNT1), 1995–97 (HUNT2) and 2006–08 (HUNT3). Data collection is complete and the participation rate in the HUNT1 for patients diagnosed with dementia was 86%. The sub-studies in the HMS are focused on examining risk factors, caregiver burden, healthcare consumption and economic consequences of treating and having dementia. Researchers interested in the HMS study are invited to contact HUNT at hunt@medisin.ntnu.no.

Key words: Dementia, health and memory, HUNT study
Why was the Health and Memory Study (HMS) in Nord-Trøndelag County, Norway, set up?

There are approximately 70,000 people living with dementia in Norway. Cognitive decline, functional impairment and altered behaviour are well-known hallmark symptoms of dementia. For patients and their caregivers, however, coexisting neuropsychiatric symptoms (NPS), such as depression, anxiety, psychosis, aggression and apathy, are perhaps even more distressing than are cognitive decline alone. Patients suffering from dementia with NPS are usually associated with earlier institutionalization, increased cost of care and a higher level of caregiver burden. In Norwegian nursing homes, 72–75% of patients with dementia have a clinically significant NPS.

Dementia may be caused by several diseases, the most common being Alzheimer’s disease (AD), vascular dementia (VaD), frontotemporal dementia (FTD) and dementia with Lewy bodies (DLB). Apart from old age, which is a risk factor for dementia in general, different dementia diseases pose different risk factors. AD is associated with genetic polymorphisms of the gene coding for the apolipoprotein E ε4 allele, depression earlier in life and cerebrovascular risk factors such as hypertension and high serum cholesterol. The strongest risk factors for VaD are hypertension, diabetes, dyslipidaemia and adiposity, and the best described risk factor for FTD is causal mutations in five genetic loci. Finally, established risk factors for DLB are genetic polymorphisms of the gene coding for the apolipoprotein E ε4 allele and male gender.

Neighbouring Scandinavian countries have national dementia registries that are used for epidemiological studies on risk factors for dementia. A comparable national dementia registry has yet to be founded in Norway. In 2007, a collaborative group was organized to begin planning a dementia panel in Nord-Trøndelag County: the Health and Memory Study (HMS). The collaborative group included representatives from the Norwegian Institute of Public Health, the Nord-Trøndelag Hospital Trust, Inlandet Hospital Trust, the Nord-Trøndelag County Health Officer, the Norwegian Association of Local and Regional Authorities, and the Faculty of Medicine at the Norwegian University of Science and Technology (NTNU). Formal approvals were obtained from the Data Inspectorate and the Regional Committee on Medical and Health Research Ethics in Mid-Norway.

The HMS was subsequently formed for the purpose of identifying persons with dementia within Nord-Trøndelag County, so that HUNT survey data, a population-based health study of Nord-Trøndelag comprising 125,000 individuals, could be utilized to analyse dementia in this population and reveal prospective exposure data for epidemiological studies. Data for the HUNT study were collected in three major health surveys in Nord-Trøndelag County: HUNT1 (1984–86); HUNT2 (1995–97); and HUNT3 (2006–08). All HUNT data are linked to a unique personal identification number given to each Norwegian citizen at birth. Although the HUNT survey provides extensive health status information, neither cognitive assessment nor dementia were priorities of the original HUNT surveys, apart from HUNT3, which included nine questions addressing memory in a self-reporting questionnaire. The design of the HMS allows for studies of dementia prevalence in Norwegian nursing homes, and a secondary aim of the nursing home panel is to analyse the association between dementia and quality of life, NPS, depression, use of medication and mortality.

Who is in the Health and Memory Study (HMS)?

The HMS consists of two datasets that can be used together or independently. These are: (i) patients with dementia...
(n = 920), identified from hospital records of individuals referred to memory clinics in the two hospitals of the county, Levanger Hospital and Namsos Hospital, during 1995–2010; and (ii) patients with dementia (n = 620) examined in the nursing homes in Nord-Trøndelag County during 2010–11.

The hospital dementia panel of the HMS

The hospital dementia panel of the HMS was established by collaboration between the memory clinics at Namsos Hospital and Levanger Hospital, which together have served all municipalities in Nord-Trøndelag County since the mid 1990s. Specialists within geriatric medicine and old-age psychiatry were responsible for the diagnostic work-up. Assessments were performed according to national and international guidelines and based upon both patient and caregiver history, clinical examinations, neuropsychological assessments, blood samples and imaging of the brain. Due to the retrospective design of the data collection, an informed consent for inclusion in the study was not possible. Approval for this design was obtained from the Regional Committee on Medical and Health Research Ethics in Mid-Norway. During the period 1995–2010, there were 1259 patients referred to memory clinics for an assessment of cognitive decline. Patients who lacked sufficient journal documentation or were duplicates were excluded, and a total of 1027 patients comprise the hospital dementia panel of the HMS. Of these 1027 participants, 107 (10.4%) were found not to have dementia and were excluded from the panel. Among those 107 participants, 78 (7.6%) were diagnosed with mild cognitive impairment (MCI). Of the 920 patients with dementia, 44.6% were classified as AD, 17.7% as VaD, 12.6% as mixed AD/VaD, 2.5% as FTD, 4.5% as DLB and 18.1% had other or unspecified dementia (Figure 1 and Table 1).

The nursing home dementia panel of the HMS

The second dementia panel of the HMS was designed to include patients from nursing homes in Nord-Trøndelag, for a study focusing on dementia, neuropsychiatric symptoms and psychotropic drug use. All 24 municipalities in Nord-Trøndelag participated in the study, and patients from all nursing homes of the county were included. Patients were eligible for inclusion if they had stayed in a nursing home for at least 14 days. The patients or, in case of a limited capacity to consent, their next of kin were informed about the study by personal letters, each with an information folder and an invitation to participate in the study. If residents were unable to give informed consent, the next of kin was invited to sign a written consent form. Whether patients could give consent was determined by the nursing home health workers. For 62% of participating patients, consent was given by the next of kin.

Of the 1082 nursing home patients in Nord-Trøndelag,17 a total of 979 patients were eligible for inclusion. Of these, 259 were excluded either because the patient or his or her relative declined participation (n = 197), the patient suffered from severe somatic disease (n = 24), death occurred before data collection (n = 17) or the patient moved out of the nursing home before the assessment commenced (n = 1). In 20 cases the reason for excluding the patient from participation was not specified, and a total of 720 patients in the nursing homes were assessed for cognitive decline. Whereas 620 patients (86.2%) were

<table>
<thead>
<tr>
<th>Dementia classification of participants in the hospital dementia panel (%)</th>
<th>1995-2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease (AD): n = 410 (44.6)</td>
<td></td>
</tr>
<tr>
<td>Vascular dementia (VaD): n = 163 (17.7)</td>
<td></td>
</tr>
<tr>
<td>Mixed AD/VaD: n = 116 (12.6)</td>
<td></td>
</tr>
<tr>
<td>Frontotemporal dementia (FTD): n = 23 (2.5)</td>
<td></td>
</tr>
<tr>
<td>Dementia of Lewy bodies (DLB): n = 41 (4.5)</td>
<td></td>
</tr>
<tr>
<td>Other/unspecified: n = 121 (13.2)</td>
<td></td>
</tr>
<tr>
<td>Parkinson’s disease dementia (PDD): n = 25 (2.7)</td>
<td></td>
</tr>
<tr>
<td>Huntington’s disease dementia: n = 5 (0.5)</td>
<td></td>
</tr>
<tr>
<td>Down syndrome dementia: n = 5 (0.5)</td>
<td></td>
</tr>
<tr>
<td>Alcohol-related dementia: n = 11 (1.2)</td>
<td></td>
</tr>
<tr>
<td>Total: N = 920</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1. Participants with dementia in the hospital dementia panel of the Health and Memory Study (HMS) were referred from the community to geriatric and old-age psychiatry units in Nord-Trøndelag County for dementia assessment during 1995–2010.
found to have dementia, 39 patients (5.4%) had no dementia and 60 patients (8.3%) had MCI. One patient (0.1%) lacked the information necessary to reach a conclusion. Of the 620 patients with dementia, 60.5% were classified as AD, 14.7% as VaD, 6.0% as mixed AD/VaD, 13.7% as FTD, 3.9% as DLB and 1.3% as other or unspecified dementia (Figure 2 and Table 2).

The HUNT study

During 1984–86, every citizen of Nord-Trøndelag County who was aged 20 years or older was invited to participate in a general health examination (HUNT1), and 77,212 persons (89.4%) participated in the survey.14 During 1995–97, all citizens aged 20 years or older were invited to participate in a second general health examination (HUNT2), and 65,237 persons participated (69.5%).15 During 2006–08, the population was again invited to participate in a general health examination (HUNT3), and out of 93,860 adults eligible for participation, 50,807 participated (54.1%).16

All data collected during the HUNT surveys are based on written informed consent, and all studies were approved by the Data Inspectorate and the Regional Committee on Medical and Health Research Ethics of Norway.

How often have they been followed up?

Cognitive assessment for the hospital-assessed participants occurred between 1995 and 2010 and for nursing home participants in 2010 or 2011. The design of this study is retrospective and unique, as HMS allows for both nursing home-assessed participants and memory clinic participants to be linked to data from the HUNT study.

Data from participants in the HMS will be linked with data from matched controls who have participated in the HUNT study, which allows for epidemiological studies on risk factors for dementia.

What has been measured?

The HUNT study

The HUNT study integrates both family and individual data and can be linked to national health registries. Repeated examinations and follow-up of the same population provide opportunities to determine changes in health and vital status. The study was primarily set up to address arterial hypertension, diabetes, screening of tuberculosis, and quality of life. Since the first wave, it has developed into containing extensive health survey status of an individual and his or her biological material. The data collected in HUNT1, HUNT2 and HUNT3 are summarized in Table 3: see Holmen et al. (1990 and 2003) and Krokstad et al. 2012 for details.14–16 It is possible to link data from the HMS to individual information from a number of regional registries (e.g. myocardial infarction, stroke, hip fractures and forearm fractures) and from national registries, such as information on education, income, and occupation.17 Other linked data include diagnostic data and date of death from the Cause of Death Registry18 and the Norwegian Patient Register,19 prescription of medication from the Norwegian Prescription Database17 and Statistics Norway’s events database (FD-Trygd) with information on all types of social security benefits.17
The Family Registry identifies who in the Norwegian population is related (parent, offspring, sibling) with whom. Altogether, endpoint data in the HMS are linked to the HUNT database in order to examine a large variety of risk factors for dementia, in part measured a long time before the dementia onset.

Dementia measurement in hospital-assessed HMS participants

For the hospital dementia panel, data on aetiological dementia diagnosis have been collected, as well as time of disease debut. Establishing the dementia diagnosis followed a two-step procedure. First, a computerized search of the two hospitals’ patient databases identified patients diagnosed with dementia at the Namsos hospital, Department of Geriatrics and at the Levanger hospital, Department of Old Age Psychiatry, from January 1995 to December 2010. A standard questionnaire was used to gather data from the hospital records of these patients. Second, four specialists in geriatrics and old-age psychiatry examined the medical records from both the first assessment and later hospital visits to verify the diagnosis of dementia, to establish the age at symptom debut and, if possible, to classify the dementia disorder. The ICD-10 criteria were applied to establish an aetiological diagnosis.

Table 2. Distribution of dementia and participation in HUNT1, HUNT2 and HUNT3 for patients in the nursing home dementia panel in the Health and Memory Study (n = 620)

<table>
<thead>
<tr>
<th>Dementia diagnosis</th>
<th>Number of patients with dementia (%)</th>
<th>Participation in at least one HUNT survey (%)</th>
<th>Participation in HUNT1 (%) 1984–86</th>
<th>Participation in HUNT2 (%) 1995–97</th>
<th>Participation in HUNT3 (%) 2006–08</th>
</tr>
</thead>
<tbody>
<tr>
<td>All cases</td>
<td>620 (100.0)</td>
<td>580 (93.5)</td>
<td>555 (89.5)</td>
<td>489 (78.9)</td>
<td>141 (22.7)</td>
</tr>
<tr>
<td>Alzheimer’s disease (AD)</td>
<td>375 (60.4)</td>
<td>356 (94.9)</td>
<td>341 (90.9)</td>
<td>304 (81.1)</td>
<td>85 (22.7)</td>
</tr>
<tr>
<td>Vascular dementia (VaD)</td>
<td>91 (14.7)</td>
<td>89 (97.8)</td>
<td>86 (94.5)</td>
<td>73 (80.2)</td>
<td>28 (30.8)</td>
</tr>
<tr>
<td>Mixed AD/VaD</td>
<td>37 (6.0)</td>
<td>32 (86.5)</td>
<td>31 (83.8)</td>
<td>25 (67.6)</td>
<td>7 (18.9)</td>
</tr>
<tr>
<td>Frontotemporal dementia (FTD)</td>
<td>85 (13.7)</td>
<td>75 (88.2)</td>
<td>69 (81.2)</td>
<td>63 (74.1)</td>
<td>13 (15.3)</td>
</tr>
<tr>
<td>Dementia of Lewy bodies (DLB)</td>
<td>24 (3.9)</td>
<td>22 (91.7)</td>
<td>22 (91.7)</td>
<td>19 (79.2)</td>
<td>7 (29.2)</td>
</tr>
<tr>
<td>Other/unspecified dementia</td>
<td>8 (1.3)</td>
<td>6 (75.0)</td>
<td>6 (75.0)</td>
<td>5 (62.5)</td>
<td>1 (12.5)</td>
</tr>
</tbody>
</table>

HUNT, the Nord-Trøndelag Health Study.

Figure 2. Participants with dementia in the nursing home dementia panel of the Health and Memory Study (HMS). All residents living in nursing homes in Nord-Trøndelag were invited for assessment during 2010–11. There were 106 participants identified as having dementia in nursing homes across the region, each of whom underwent dual assessment in geriatric or old-age psychiatry departments.
of AD and VaD. DLB was diagnosed according to the DLB consortium criteria and FTD was diagnosed according to the Manchester-Lund criteria. A conservative approach was chosen when classifying VaD, and only patients with a symptomatic cerebrovascular disorder and a subsequent dementia were classified as VaD. Those with clinical AD and vascular changes at a CT/MRI scan were classified as mixed AD/VaD. In addition, data on CT/MRI scans, blood tests, comorbid somatic and psychiatric diseases, smoking, alcohol consumption, cognitive function and depressive symptoms have been collected. Information on medication prescribed at the time of dementia diagnosis has been registered.

Dementia measurement in the nursing home participants of HMS

Dementia assessment in the nursing home began in June 2010 and was completed in March 2011. Nine registered nurses with adequate clinical experience performed the assessments by conducting a standardized interview with the patients, their closest professional caregiver and their closest relative(s). Prior to collecting data, the nurses received a 2-day training course on the use of the assessment scales. The project leader was available for consultation throughout the data collection period. Cognitive function was assessed by two cognitive tests: the Mini-Mental-State Examination (MMSE) and the Severe Impairment Battery-8 (SIB-8), and by interview with the relative(s) using the Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE). Dementia was assessed by interview with a professional caregiver using a questionnaire for identifying dementia symptoms developed for this study, as well as the Clinical Dementia Rating Scale (CDR). Neuropsychiatric symptoms were assessed with the Neuropsychiatric Inventory (NPI) and symptoms of depression were assessed with the Cornell Scale for Depression in Dementia (CSDD). The patients’ quality of life was assessed with the

Table 3. Measurements in HUNT1, HUNT2 and HUNT3

<table>
<thead>
<tr>
<th>Phase</th>
<th>Measurements</th>
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<tbody>
<tr>
<td>Baseline HUNT1</td>
<td>Questionnaires (four): self-reported health, quality of life, illness, diseases (e.g. cardiovascular diseases and diabetes mellitus), major behavioural risk factors and socio-economic position. Disease-specific questionnaires for hypertension, diabetes and quality of life. Anthropic measures: weight and height. Biological tests: blood pressure and heart rate, chest-X-ray (subgroups), capillary non-fasting blood glucose (for participants 40 years and older and participants with known diabetes), and venous blood samples analysed for total HbA1 in persons reporting known diabetes.</td>
</tr>
<tr>
<td>1984–86 (n = 77 212)</td>
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</tr>
<tr>
<td>Follow-up (I)</td>
<td>Questionnaires (eight): self-reported health, quality of life, illness, diseases (several), major behavioural risk factors and socio-economic position. Disease-specific questionnaires for hypertension, diabetes and lung diseases. Assessment of depression and anxiety, the Hospital Anxiety and Depression Scale (HADS) and other items assessing symptoms of anxiety and depression. Anthropic measures: weight, height and circumference of waist and hip. Biological tests: blood pressure and heart rate. For sub-groups: spirometry, forearm bone mineral density (BMD) and vision. Venous blood samples: cholesterol [total and high-density lipoprotein (HDL)], triglycerides, glucose, serum iron, transferrin and creatinine. For sub-groups: thyroid-stimulating hormone (TSH), calcium and parathyroid hormone (PTH). Stored as serum aliquots at −80°C with DNA extracted.</td>
</tr>
<tr>
<td>1995–97 (n = 65 237)</td>
<td></td>
</tr>
<tr>
<td>Follow-up (II)</td>
<td>Questionnaires (seventeen): self-reported illness, diseases (several), major behavioural risk factors and socio-economic position. Anthropic measures: weight, height and circumference of waist and hip. Biological tests: blood pressure and heart rate. Sub-groups: spirometry, BMD (forearm, hip and lumbar), max O2-uptake, echocardiography and dental status. Venous blood samples: cholesterol (total and HDL), glucose, triglycerides, TSH and other. All were analysed and stored as serum aliquots at 80–180°C.</td>
</tr>
<tr>
<td>2006–2008 (n = 50 807)</td>
<td></td>
</tr>
<tr>
<td>HUNT2</td>
<td>Anthropic measures: weight, height and circumference of waist and hip. Biological tests: blood pressure and heart rate. For sub-groups: spirometry, forearm bone mineral density (BMD) and vision. Urine (sub-groups): micro-albumin and creatinine.</td>
</tr>
<tr>
<td>HUNT3</td>
<td>Anthropic measures: weight, height and circumference of waist and hip. Biological tests: blood pressure and heart rate. Sub-groups: spirometry, BMD (forearm, hip and lumbar), max O2-uptake, echocardiography and dental status. Venous blood samples: cholesterol (total and HDL), glucose, triglycerides, TSH and other. All were analysed and stored as serum aliquots at 80–180°C.</td>
</tr>
<tr>
<td>2006–2008 (n = 50 807)</td>
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HUNT, the Nord-Trøndelag Health Study.
Quality of Life in Late-Stage Dementia (QUALID) and personal activities of daily living were assessed by the Physical Self-Maintenance Scale (PSMS). Caregiver distress was assessed by the Relative’s Stress Scale (RSS).

In addition, two physicians with wide clinical and research experience independently diagnosed MCI, the dementia syndrome and dementia subtypes, using all available information. If the two physicians disagreed about a diagnosis, a third expert was consulted to reach consensus. The same criteria for dementia and aetiological dementia diagnosis were used as for the hospital dementia panel.

Of the 620 patients diagnosed with dementia in nursing homes, 106 patients had already been diagnosed with dementia in the hospital dementia panel. Therefore, a total of 1434 individuals were classified with dementia in the HMS. Thirty-seven of the 106 patients classified in both the hospital and nursing home dementia panels were given different aetiological dementia diagnoses in the two settings. If discrepancy occurred in the dementia diagnoses from the hospital workup and the nursing home assessment, priority was given to the diagnoses from the hospital, since the hospital diagnoses were based on a clinical examination by a physician whereas the nursing home diagnosis was based solely on a review of data collected by the nurses.

**What has it found? Key findings and publications**

The numbers of patients with various dementia diagnoses from the hospital and the nursing home dementia panel participating in HUNT1, HUNT2 and HUNT3 are shown in Tables 1 and 2, respectively. Of the 920 patients diagnosed with dementia at the hospitals, 89.7% participated in at least one of the HUNT surveys, whereas 93.5% of the 620 patients diagnosed with dementia in the nursing homes participated in at least one of the HUNT surveys. The main aim of the HMS is to explore risk factors for dementia. A secondary aim is to examine the association between dementia and quality of life, NPS, depression, use of medication and mortality in the nursing homes. Participants in the HMS not participating in any of the HUNT surveys will be included in the analyses of the nursing home data and in analyses where only registry data, not HUNT data, are used as predictors of dementia.

Thus far, two articles have been published based on the described dementia panels. The first article presented the prevalence of neuropsychiatric symptoms in nursing homes in Nord-Trøndelag County. The main finding in this study was that dementia was prevalent in Norwegian nursing homes (82%), and that 75% of the patients with dementia had at least one clinically significant NPS (Figure 3). The most prevalent NPS were delusion, apathy and irritability, and rates of dementia among nursing home residents where comparable to a previous Norwegian study of 933 nursing home patients with dementia, indicating that data from the dementia panel can be generalized to other populations. The second article presented the association between headache and dementia. Baseline data on headache from the Nord-Trøndelag Health Study (HUNT 2) performed during 1995–97 were categorized as headache free, with any headache, with migraine and with non-migrainous headache. Data from the hospital dementia register were the endpoint, and dementia was classified as AD, VaD, mixed AD/VaD, FTD or DLB. Hazard ratios (HRs) for later inclusion of the headache cases in the dementia register were estimated using Cox regression analysis. Compared with those who were headache free, participants with any headache had increased risk of VaD and of mixed dementia (AD/VaD). No association between any headache and later development of AD was found.

The distributions of aetiological dementia diagnoses in the hospital panel and the nursing home panel differ. AD, FTD and DLB were all more prevalent in patients in the nursing homes compared with patients diagnosed in the hospitals, whereas VaD was more prevalent in the hospitals. Several explanations are possible. First, patients living in nursing homes are different from patients referred to a hospital memory clinic. Patients with DLB or FTD may...
be more in need of the treatment and care provided in nursing homes than patients with AD and VaD, who more often can be cared for at home. Secondly, a patient’s symptoms of dementia change as the disease progresses, but diagnosis should be based on the symptoms and signs presented early in the course of the disease. This fact more often complicates the diagnosis of patients with severe dementia than of patients with mild or moderate dementia. Diagnosing specific dementia diseases, such as FTD and LBD, in patients living in nursing homes is therefore more difficult than diagnosing patients in hospital outpatient clinics, although the dataset from the nursing homes included information on symptoms early in the course of the disease. Patients with AD will develop symptoms and behaviour similar to patients with LBD and FTD later in the course of their diseases, and are therefore often incorrectly diagnosed with FTD or DLB if diagnosed late in the course of the disease. The number of patients diagnosed with FTD or LBD in the nursing homes may therefore be too high.

What are the main strengths and weaknesses?

The chief strength of the HMS is the possibility to link individual dementia data with data from the HUNT database. Since 1984, HUNT has collected data from a total county population in three extensive health surveys. Few other studies on the risk factors for dementia offer predictive data collected three decades ago. Furthermore, data from the first HUNT survey are also probably the most representative of the entire HUNT data, since the participation rate in HUNT1 was close to 90%. The HUNT study includes a broad variety of exposure variables relevant to the study of dementia, which can be further extended by including registry data. Another strength of HMS is the relatively large number of individuals with dementia collected both from hospital files and from nursing homes. Data were registered using standard and validated measures and were collected by a small group of experienced nurses. In addition, HUNT2 includes biological material from the participants, which allows for biological analyses. Altogether, linking these studies offers a solid research platform to perform a variety of studies on dementia.

Nevertheless, there are limitations to the study. For a proportion of the participants (10.3% of the hospital dementia panel and 6.5% of the nursing home dementia panel) there are no data on the risk factors observed in the HUNT.

Another limitation is that hospital data were recorded retrospectively. Though most patients referred to hospitals were examined by multiple doctors who implemented standard routines, some files had missing data, which may have reduced the reliability of some diagnoses. The nursing home dementia panel also had some limitations. The diagnosis of dementia was based on a review of the data collected from the patients, their family members, and their caregivers. There were also some data missing in the material from the nursing homes, which somewhat reduced the validity of the diagnoses. However, the two physicians with wide clinical and research experience did find that the data were sufficient to make a diagnosis according to established criteria. Also in the nursing homes, a substantial number of residents were excluded due to poor somatic or mental health or because the residents or their families chose not to participate.

The HMS includes patients from nursing homes and from hospital outpatient clinics, but does not include patients diagnosed with dementia by general practitioners or assessed by other healthcare workers at a primary care level. Both patients diagnosed at a hospital level and patients admitted to nursing homes have a more severe dementia than patients diagnosed in the primary care system. The selection of participants to the HMS may therefore be biased, and generalization from the HMS to the general dementia population in Norway may be a limitation of the study.

Data from participants with dementia in the HMS are compared with data from healthy controls in the HUNT study. A weakness of the study is that not all the people in the county diagnosed with dementia during the observation period 1995–2011 have been identified. But even if the number of false negatives approaches the number of true positives in the HUNT sample, the risk estimates will only be moderately deflated. This is because the undetected dementia cases will only constitute a small fraction of the subjects assumed to be non-cases, such that the contamination of the non-case group will only slightly affect the observed difference in risk factors between the alleged cases and non-cases. As an example we might assume that in an elderly part of the population the real prevalence of dementia is 10%, the prevalence of hypertension 30 years earlier was 6% and the real odds ratio for dementia in hypertensive persons compared with normotensive persons is 3.00. In this example, if only 2/3 of the dementia cases could be identified and 1/3 were left undetected as false negatives, the estimated odds ratio would only be downwards biased from 3.00 to 2.85.

One final limitation of the HMS is that data from hospitals were ascertained during 1995–2010, whereas data from nursing homes were collected during 2010–11. Information on time of dementia onset is registered both in the nursing home dementia panel and in the hospital.
dementia panel, which will be important for future research. However, as the knowledge of and research on dementia have developed significantly over the past decades, diagnostic criteria for aetiological dementia have changed. Another, even more severe, implication of this ascertainment procedure is that the proportion of cases in the population that were detected probably increased substantially during the observation period. This will complicate survival analysis of the data.

The inclusion of patients in the dementia panel continues, as prospective data collections on patients in the nursing homes and in hospital outpatient clinics are ongoing and will extend the dementia panels in the future.

Can I get hold of the data?

At the moment the funding institutions are granted an exclusive right to perform studies on data from the dementia panel, but at a later point in time offers of collaboration from researchers outside our current research group will be welcome. Information about application procedures is available on request, at: hunt@medisin.ntnu.no.

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The organization and the data collection of HMS have been funded by the Norwegian Institute of Public Health, the Norwegian University of Science and Technology (NTNU), Nord-Trøndelag Hospital Trust and Innlandet Hospital Trust.

Author contributions

S.B. participated in the design of the study, contributed to the sub-classification of dementia diagnosis in the hospital and nursing home dementia panels and drafted the manuscript. J.H. was Principal Investigator (PI) of the HUNT Study from 1984 to 2008, served as head of the collaborating dementia study group during 2007–11 and participated in the design of the study. J.G. performed statistical analyses. E.S. participated in the design of the study and contributed to the sub-classification of dementia diagnosis in the hospital dementia panel. G.S. participated in the design of the study and contributed to the sub-classification of dementia diagnosis in the hospital dementia panel. I.S. participated in the design of the study and contributed to the sub-classification of dementia diagnosis in the hospital dementia panel. A.F. participated in the design of the study and contributed to the sub-classification of dementia diagnosis in the hospital dementia panel. E.L. participated in the design of the study and performed statistical analyses. K.T. participated in the design of the study and performed statistical analyses. All authors have read and approved this manuscript.

Conflict of interest: G.S. has given lectures on seminars sponsored by pharmaceutical companies. Participation by I.S. in conferences has been sponsored by pharmaceutical companies.

References


