DZNE
Deutsches Zentrum für
Neurodegenerative Erkrankungen
in der Helmholtz-Gemeinschaft

Third Workshop on Monitoring Dementia

"New Insights From Health Claims Data and Electronic Medical Records"

17th/18th October 2018 in Bonn, Germany

ABSTRACTS (ordered by session)

Session 1, Wednesday, October 17, 10:45-12:15

Prof. Vanessa Didelez

Title:

Causal Inference for Pharmacoepidemiology

Abstract:

In this presentation I will review challenges, and possible solutions, regarding causal inference from the kind of data typically analysed in Pharmacoepidemiology, in partciular secondary / registry data. Important aspects are: How to define a causal research question and how this should guide the statistical analysis; Fallacies regarding the conceptualisation of exposure or treatment, when in reality this is mostly time-varying; Different methods of adjusting for (time-varying) confounding beyond propensity score matching; Approaches addressing unobserved confounding, such as instrumental variables or bias modelling / sensitivity analysis. The issues will be illustrated with examples from the German Pharmacoepidemiological Research Database (GePaRD).

Michael Nerius, Uta Ziegler, Anne Fink, Gabriele Doblhammer

Title:

Prevalence and Trends of Dementia and Parkinson's disease based on comprehensive German health claims data.

Abstract:

Background: Dementia and Parkinson's disease are the most common neurodegenerative diseases at old age. So far, estimations of prevalences and trends in Germany may be biased because (1) community-based surveys mostly cannot reach institutionalized and critically ill persons which leads to an underestimation and (2) studies based on health claims data from single health insurance funds lack representativeness which might also leads to under- or even overestimation of the respective disease.

Methods: We used newly available health claims data sets of the years 2009–2012 comprising all Germans insured in statutory health insurance funds reflecting 86% of the German population. The analysis population consisted of 14.8 million persons aged 65 to 90+ living in their community or in

nursing homes. Crude and age-standardized prevalences for dementia and Parkinson's disease were calculated for both sexes. The time-trend was estimated using a negative binomial regression.

Results: In 2012, the crude prevalence for dementia was 7.9% and for Parkinson's disease 2.2% (65+ population). Over all ages, the yearly decline in dementia was 0.7% (RR=0.993, p=0.024) among men and 1.4% (RR=0.986, p=0.001) among women. Parkinson's disease trends were significant among women (RR=0.995, p=0.032) but not among men (RR=1.003, p=0.339).

Conclusions: Using newly available health claims data sets we were able to assess an up-to-date-picture of dementia and Parkinson's disease in Germany. For dementia, we could demonstrate a decline among both sexes, albeit starting at different ages. A reduction of the dementia prevalence could partially counterbalance the increase of people with dementia due to population ageing. For Parkinson's disease we find decreasing prevalences only among women.

Catherine Pelletier

Title:

Health administrative data linkage for national surveillance of dementia: Methods, data and future developments of the Canadian Chronic Disease Surveillance System.

Abstract:

Background: Dementia is a growing public health challenge, globally. In Canada since 2016, an innovative system, the Canadian Chronic Disease Surveillance System (CCDSS), enables surveillance of diagnosed dementia, including Alzheimer's disease. This presentation will illustrate how routine healthcare data are linked to provide valid evidence on dementia among Canadian seniors. Forthcoming CCDSS developments for enhanced surveillance of dementia will also be presented.

Methods: The CCDSS is a pan-Canadian partnership among all provinces and territories supported by the Public Health Agency of Canada. It uses linked health administrative databases to collect data on 20+ chronic conditions.

A validated algorithm identifies cases of diagnosed dementia among Canadians (65+ years) when they have:

- 1+ hospitalization records or 3+ physician claims within 2 years (minimum 30 days between each claim) with an ICD code for dementia; or
- 1+ anti-dementia drug prescriptions.

Results: Dementia incidence, prevalence and all-cause mortality data will be presented by 5-year age groups to quantify the increasing burden with aging, and by sex to illustrate the gender differential. All-cause mortality rate ratios will provide information on the higher mortality faced by a population affected by dementia. For all indicators, trends over time will be shown.

The CCDSS is an evergreen system and various areas are being explored to enhance dementia surveillance, including:

- Estimation of healthcare costs incurred by seniors with dementia;
- Comorbidity/multimorbidity among seniors with dementia;
- Short-term projections of dementia;
- Surveillance of early onset dementia.

For these areas under development, current work, new methods, preliminary data, and/or challenges will be presented, as applicable.

Conclusion: CCDSS data are used to monitor the epidemiological burden of dementia in Canada and to support better planning of health resources, the development and implementation of evidence-based health policies, and program evaluations. Surveillance data can also provide evidence that helps identify knowledge gaps and generate research questions.

Session 2, Wednesday, October 17, 13:30-15:00

Prof. Kristina Johnell

Title:

Monitoring dementia in Sweden: findings from nationwide registers.

Abstract:

In Sweden, about 150 000 individuals suffer from dementia and 2/3 of them have Alzheimer´s disease. To achieve a dementia care of similar and high quality in the whole country, the national quality registry for patients with dementia disorders, The Swedish Dementia Registry (SveDem), was initiated in 2007.

SveDem currently includes almost 80 000 dementia patients and represents one of the largest dementia cohorts in the world. One unique feature of SveDem is the possibility to study the more rare dementia disorders (e.g. dementia with Lewy bodies and Parkinson's disease dementia). Patients newly diagnosed with a dementia disorder are registered and followed-up annually. Variables include socio-demographics, type of dementia disorder, dementia work-up investigations, heredity, BMI, Mini Mental State Examination (MMSE) scores and drug treatment. Data from SveDem can be merged with other registers to include more information about the patients.

I will present research based on SveDem and other nationwide registers. Focus will be on drug treatment of dementia patients. Dementia patients typically have multiple diseases, use many medications (polypharmacy) and are at high risk of adverse drug events. There is a need for research about the benefits and harms of drug therapy in people with dementia to achieve more effective use of medications.

The large nationwide registers in Sweden allow us to circumvent the shortcomings of smaller studies based on selected samples. We are able to study rare exposures and outcomes, such as individual

drugs, with high statistical precision. Thus, our findings contribute to increasing the knowledge about dementia in the real-world setting.

Dr. Kathryn Richardson

Title:

Using the UK Clinical Practice Research Datalink for dementia research.

Abstract:

The Clinical Practice Research Datalink (CPRD) allows researchers to access primary care records from 17 million patients that are generally representative of the United Kingdom population. In the UK primary care acts as a gate-keeper and a hub for access to most medical services and so this is an extremely valuable resource to answer many different research questions. Coded data on consultations, diagnoses, tests, referrals, prescribed medications and findings returned from secondary care services are available. Linkage is available from CPRD to other datasets, in particular hospital records and social deprivation indices. We are using CPRD for five dementia epidemiology studies. In this talk I will briefly share my experience of two studies. First, a nested case-control study examining classes of anticholinergic medications and long-term risk of dementia. Second, a cohort study using CPRD linked to hospital admission records to examine adverse events due to Z-drug (zolpidem, zopiclone and zaleplon) use for sleep disturbance in dementia. Our group is also examining risk factors for incident pneumonia, adverse events from hypoglycaemia, and the effect of regular medication reviews on drug burden for people with dementia. Many other types of questions could be answered. There are limitations when using primary care data for dementia research. First, the data is not recorded with research in mind, so may not always record information in the way you would prefer. It also needs careful coding and checking before use. There is no standardised diagnosis for dementia, and diagnoses may be missed or delayed. There are also very few records of cognitive assessments, such that we need to rely on diagnosis data. Ideally, data managers or statisticians experienced with similar datasets should be employed to work with CPRD data, owing to its complexity.

Prof. Britta Haenisch

Title:

Pharmacoepidemiological analyses and drug safety.

Abstract:

Pharmacoepidemiology analyzes the use and the effect of drugs in populations. One focus of pharmacoepidemiological research is the evaluation of patterns and determinants of drug response and adverse drug events in clinical and population-based settings in different patient groups, e.g. elderly patients or distinct clinical phenotypes. The aim is to assess efficiency and safety of pharmacotherapy. Furthermore, risk constellations in view of different treatments with multiple

drugs can be detected. Thus, pharmacoepidemiological analyses contribute to drug safety and provide a basis for further decisions in health care policy. Polypharmacy increases the risk of adverse drug events and can accelerate cognitive decline and care dependency in elderly patients. Therefore, it is important to detect possible interventions which are able to prevent or at least delay the onset of cognitive decline or long-term care in the elderly population. The detection of risk factors is essential to apply primary prevention in drug therapy. Different data sources are used, including primary data from clinical cohort studies as well as secondary data from public health insurance. This allows to conduct comprehensive pharmacoepidemiological analyses on drug use with data from applied clinical research and claims data. Direct combination of primary and secondary data can be an useful tool for pharmacovigilance issues and precision medicine. The combination of pharmacogenetics and pharmacoepidemiology allows to examine the influence of metabolic profiles on drug safety in routine care and on the use of health insurance services. The aim is to use medical services and medication more accurately and individually to increase the quality of drug therapy and patient care and to decrease the number of adverse drug events.

Session 3, Wednesday, October 17, 15:30-17:00

Dr. Marcello Ienca

Title:

Dementia, Digitalisation and Big Data: Aligning Science, Healthcare and Policy for Patients' Benefit.

Abstract:

The increased availability of digital data combined with rapid advances in data analytics are creating the possibility for collecting, transmitting, aggregating and analysing unprecedented volumes of heterogeneous and differently structured data, a phenomenon known as big data. The application of big data trends to dementia research holds the potential for improving our understanding of Alzheimer's disease, other dementias of ageing, and the ageing brain, accelerating clinical research, improving prevention and diagnostics and optimising the delivery of care. At the same time, due to their methodological novelty and computational complexity, these trends raise a number of technical, scientific, ethical and regulatory challenges. These include producing adequate standards of evidence for data-driven research as compared to conventional clinical research methods, developing digital infrastructures and ethical safeguards for safe and secure data sharing, preventing algorithmic bias and discrimination, removing obstacles that delay the translation of clinically effective technologies and methods while preserving patients' privacy and autonomy. This contribution will synthesise both the relevant scientific literature and emerging policy frameworks (e.g. at the OECD level) to map the promises and challenges of big data trends in dementia research. Based on this synthesis, a set of evidence-based recommendations aimed at aligning science, technology, medicine, ethics and policy for the benefit of patients will be proposed.

Dr. Alejo Nevado-Holgado

Title:

Neural network extraction of mental health terms from text in electronic health records.

Abstract:

Mental disorders affect a large proportion of the population. Most of the medical information about these conditions is hidden in the form of text in Electronic Health Records (EHRs) such as UK-CRIS (https://crisnetwork.co/), the largest network of secondary care mental patient records with 14 NHS trusts. Due to the size of these EHRs, information extraction from text needs to be automatized through Natural Language Processing (NLP). In this presentation we will demonstrate a number of NLP methods that we have developed in the last year to extract diagnoses, medications, scores in tests of mental health, and relationships between terms. We focus specially on the case where few annotated examples are available, which is a specially important challenge in medical data. The methods include both neural networks and rule engines, while the used datasets include UK-CRIS, i2b2 and SemEval. We achieve F1 extraction performance ranging from 81.48% to 98.05%.

Dr. Juliane Fluck

Title:

Semantic integration of multimodal data at the DZNE

Abstract:

The key aim of the BMBF-funded project IDSN is to enable scientists to integrate and query data from different DZNE research fields and complement this with secondary disease information and biomedical databases. We accomplish this task with the following steps: (1) By using a semantic lookup service that facilitates interoperability and encloses all semantic concepts needed for data integration, (2) incorporation and analysis of longitudinal electronic patient information from unstructured records such as clinical and cognitive testing reports, (3) generation of semantic layers for the genetic, pharmacological and phenotypical datasets, (4) integration of existing pathway and disease knowledge bases with the vast amount of unstructured information hidden in publications and (5) concept mapping and query building together with dedicated result visualisations over the different data resources within DZNE. This talk will focus on the fundamental concept, the integration of heterogeneous datasets and a first data analysis that compares hospital routine data and DZNE cohort data.

Session 4, Thursday, October 18, 09:00-10:30

Dr. Stephen Pearson

Title:

Detecting undiagnosed dementia in primary care by using machine learning

Abstract:

Diagnosis of dementia has been a government target in UK for some years. Current rates range between 40 and 70%, and there is marked service provision and follow up across UK. Using related conditions such as hypertension, diabetes mellitus, cognitive enhancer medications, which are all coded in primary care. Associated conditions in patients already diagnosed with dementia were also looked at. A machine learning process looked at associations to try and predict patients at risk of dementia. It was suggested that patients from an 'at risk' pool could be screened for a possible dementia diagnosis. Further validation of existing diagnoses is needed, as well as a validation of an at risk screened sample.

Some problems have emerged from this project. Clearly the model needs validating. There is potentially difficulty in diagnosing dementia in patients who may be unaware of this possibility. There is poor evidence base for early intervention in early cognitive impairment.

Younger patients may benefit from early diagnosis by being able to access research trials, undertake planning. This may not apply to older patients, who have frailty and comorbidities with polypharmacy. There may however, be a reduction in delirium in preventing unexpected dementia being discovered on a hospital admission.

There is difficulty in potentially detecting asymptomatic patients who 'are at risk'? Perhaps it may be better to target patients with significant dementia? A follow up study of the cohort may be a useful validation measure. There is problem in discovering false positives? There was no involvement of a user group in the project which would have been helpful as there are potentially big issues early diagnosis and uncertainty of diagnosis that need resolving. More involvement of primary care practitioners in managing study outcomes would have been helpful.

Prof. Willem A. (Pim) van Gool

Title:

Advancing towards a public health approach to prevent dementia: the preDIVA-, HATICE- and PRODEMOS-trials.

Abstract:

With life expectancy increasing worldwide, the prevalence of dementia will rise rapidly in the near future. The strong association between cardiovascular risk and all-cause dementia suggests a window of opportunity for dementia prevention.

The Prevention of Dementia by Intensive Vascular care (preDIVA) study, starting in 2006, was the first large, long-term trial in older unselected persons on the effectiveness of a multidomain cardiovascular intervention using all-cause dementia as a primary outcome. General practices were randomly assigned to a 6-year nurse-led, cardiovascular intervention in 1890 participants or to usual care (n=1636). Primary outcome data were obtained for 98% participants after a median follow-up of 6·7 years (21,341 person-years). Dementia developed in 6·5% of intervention vs. 7·0% of control participants (HR 0·92, 95%CI 0·71-1·19). Sensitivity analyses suggested lower hazard ratios for participants adherent to the intervention (0.83, 95%CI 0.62-1.11) and those with untreated hypertension at baseline (0.69, 95%CI 0.43-1.11). Currently, a long-term extension of the follow up, 10-12 years after baseline, is underway in the preDIVA population.

In the Healthy Ageing Through Internet Counselling in the Elderly (HATICE) study, starting in 2015, 2724 participants from the Netherlands, Finland or France, were randomized to an interactive Internet intervention stimulating coach-supported self-management for cardiovascular risk profile improvement (n=1389) or a sham platform (n=1335). After 18 months, complete data on the primary outcome consisting of a composite z-score based on the changes of systolic blood pressure, LDL cholesterol, and body mass index could be analysed in 88% of participants. Study results, under review in August 2018, will be discussed in more detail during the October workshop. Generally, within a public health context, even modest improvements of cardiovascular risk profiles can have substantial long-term effects at the level of older populations.

Based on the experiences with preDIVA and the HATICE results, the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project was started early 2018 building on the existing eHealth intervention that will be adapted to a mHealth platform for dementia prevention, specifically tailored to vulnerable populations. In collaboration with groups from China and the UK the platform will be implemented in multiple settings to pave the way towards a scalable strategy for dementia risk reduction worldwide.

For more information please visit: edpi.org; hatice.eu; prodemos-project.eu

Dr. Jan Pablo Burgard

Title:

Estimation of regional prevalence from health insurance claims of a non-random population.

Abstract:

The small-scale mapping of disease distributions - e.g. for dementia, diabetes mellitus, or myocardial infarction - requires comprehensive and detailed epidemiological information. Conducting surveys to gather such data is very cost-intensive. Therefore, national statistical institutes often only publish corresponding figures on higher aggregation units, such as KV-regions or federal states. A high-resolution and at the same time the low-cost alternative is prevalence data that health insurance companies collect about their policyholders. These records provide comprehensive information on how diseases are distributed locally. However, due to specific characteristics of the German health insurance market, the insurance population of an individual health insurance company cannot be

compared with that of another insurance company. A person's health insurance membership is informative with regard to the morbidity of various diseases. This implies that a direct inference based on a specific health insurance companies population to the German population as a whole is not generally valid.

We propose a correction procedure with which, under certain assumptions, the total German population can be inferred from a health insurance companies population. The procedure is presented using dementia, diabetes mellitus and myocardial infarction as examples.

Session 5, Thursday, October 18, 11:00-12:30

Dr. Anne Fink, Uta Ziegler, and Gabriele Doblhammer

Title:

Potential for prevention of dementia in Germany: An analysis of health claims data.

Abstract:

Background: Dementia is one of the most cost and care intensive illnesses of the elderly. Until now, dementia is not curable. The demographic aging in western populations will lead to an enormous increase of future dementia cases. Preventive measures to avoid or at least to postpone the onset are therefore very crucial. Recent studies have estimated the impact of potentially modifiable risk factors on the dementia burden worldwide. We aimed to provide estimates for the impact of six potentially modifiable risk factors on the future number of dementia cases in Germany.

Methods: With data from the largest German health claims insurance (AOK 2010-2015) we estimated the population attributable fractions (PAF) associated with dementia for six potentially modifiable risk factors (Hypertension ICD: I10-I15, Cerebrovascular diseases ICD: I60-I69, Ischemic heart diseases ICD: I20-I25, Diabetes mellitus ICD: E11-E14, smoking related diseases: Chronic obstructive pulmonary disease ICD: J44 and Lung cancer ICD: C34, Hearing impairment ICD: H90, H91, H93.0). We projected the future number of people with dementia taking into account a relative reduction of each of the six potentially modifiable risk factors by 10% and 20% per decade. We performed separate projections for men and women.

Results: We estimated a PAF of 36.0% (95% CI: 31.7-40.5%) for men and 34.5% (95% CI: 30.3-38.9%) for women which equates to 0.56 million attributable cases of 1.6 million total cases in Germany in 2015. A relative reduction of 10% (20%) per decade in the prevalence of each of the six risk factors could reduce the future number of dementia cases in 2055 by 9.9% (18.3%).

Conclusions: More than one third of all dementia cases are attributable to potentially modifiable risk factors in Germany. Reducing the prevalence of risk factors by implementing recommendations for a healthy life style can potentially prevent an essential number of dementia patients.

Dr. Thomas Fritze, Michael Heneka, and Gabriele Doblhammer

Title:

Sepsis and Risk of Dementia. An Analysis of German Claims Data for the years 2006-2015.

Abstract:

Dementia is a major determinant of caregiving needs and societal healthcare costs. Identifying risk factors may prevent this disease and its progression. Sepsis is a potentially fatal whole-body inflammatory state caused by severe infection and might increase the brain's susceptibility to neurodegenerative disease and risk of developing dementia. Based on event history analysis, we aim at evaluating the effect of sepsis in increasing the dementia incidence risk.

The study population consisted of 161567 persons aged 65+, using claims data of the largest German health insurer. The effect of sepsis on dementia incidence was assessed using a Cox regression model. In a longitudinal analysis the years 2004-2005 were used to verify dementia and the years 2006-2015 to analyze the risk of incident dementia diagnosis (28851 cases). We explored whether the time since last sepsis diagnosis modulates the dementia risk by distinguishing 0, 1-8, ≥9 quarters, taking into account admission to intensive care unit (ICU). Models adjusted for age, gender, cerebrovascular and vascular diseases, depression, Parkinson, delirium, and surgeries. Diagnoses were defined according to International Classification of Diseases, Tenth Revision; surgeries according to OPS-codes. Kaplan-Meier analysis was performed to determine mortality after sepsis in a case-control design.

If sepsis occurred in the same quarter as the dementia diagnosis, patients with sepsis and no intensive care had a 3.14-fold (95% CI 2.83-3.49) increased risk, patients with sepsis and intensive care a 2.22-fold (95% CI 1.83-2.70) increased risk of receiving an incident dementia diagnosis compared to patients without sepsis. The effects were attenuated after 1-8 quarters, and disappeared after 9 quarters since sepsis diagnosis. Kaplan-Meier analysis revealed an increased short-term mortality among persons with sepsis and intensive care compared to patients with sepsis and no ICU admission and patients without sepsis, indicating a selection effect in the short-term sepsis-associated dementia incidence risk.

In people surviving the high-risk phase for dementia immediately after sepsis, long-term risk of dementia may reach the level of those without sepsis. These findings encourage identifying modifiable components of hospital and rehabilitation care to alleviate the burden on patients and health care systems. Future research to identify mechanisms leading from sepsis to cognitive impairment and dementia is especially important.

Dr. Raymond Lo

Title:

Medical Comorbidity in Alzheimer's Disease.

Abstract

Background: Multimorbidity is common in older adults including patients with Alzheimer's disease (AD). Knowledge of medical comorbidity in AD will improve our understanding of the complexity in dementia care and provide hints in shared etiology.

Objective: We aimed to describe the comorbidity pattern of AD in a nested case-control study.

Methods: Our study population was a random sample of 2 million individuals in Taiwan National Health Insurance program during 2001-2011. We identified incident AD cases by International Classification of Diseases codes and further restricted cases to those diagnosed by neurologists or psychiatrists, treated with cholinesterase inhibitors or memantine of approved reimbursement. Fourteen medical comorbidities were selected based on the multiple chronic conditions reported by the US Department of Health and Human Services Office of the Assistant Secretary of Health in 2013. We sampled a set of age- and sex-matched control subjects (2: 1 ratio) and employed conditional logistic regression to estimate the associations between pre-specified 14 comorbidities and AD. The clusters of multiple chronic diseases were then identified by exploratory factor analysis.

Results: A total of 2,618 AD cases were identified during 2001-2011 with a mean age of 76.1 years and female preponderance (59%). The most common 5 comorbidities in AD were hypertension (55.1%), osteoarthritis (38.2%), depression (32.3%), diabetes mellitus (DM) (25.7%) and cerebrovascular disease (CVD) (22.7%). After adjusting for age and sex, DM, osteoporosis, depression and CVD were significantly associated with AD. The number of comorbidity was 3-fold greater in the AD group. The cluster of hypertension, DM and hyperlipidemia was the most common combination in old age, whereas the cluster osteoarthritis and osteoporosis was the only multimorbidity pattern significantly associated with AD.

Conclusion: Multimorbidity is common in AD. Depression, CVD, osteoporosis and DM are associated with incident AD, supporting that their co-existence is a typical feature of AD at old age. Comorbidity care should be integrated into current management for patients with AD.

Session 6, Thursday, October 18, 13:45-15:15

Dr. Paul Gellert

Title:

Dementia and musculoskeletal conditions predicting nursing home status in centenarians in the last six years of life

Abstract:

A large proportion of the oldest old and centenarians live in long-term care facilities. While there may be distinct care patterns in centenarians compared with other cohorts of oldest old, the exact development concerning prevalence, length of stay, and factors that are associated with long-term care status in the last years before death is unknown.

In all, 1,398 institutionalized and non-institutionalized oldest old (deceased at 80-89 [octogenarians], 90-99 [nonagenarians], or over 100 years of age [centenarians]) from Germany were included in this longitudinal analyses of health insurance data across six years before death. Long-term care status and transition from home care into long-term care over 6 years (34,740 person-quarters). Dementia, musculoskeletal diseases, multimorbidity, hospital admission, gender, and age-at-death were derived from administrative data and analyzed using binary Generalized Estimating Equations.

Although the initial level of long-term care (six years before death) was higher among centenarians (65.1% vs. 53.6% in nonagenarians; 36.2% in octogenarians), the rate of increase was stronger in the younger cohorts. Distinguishing between long-term care escapers, delayers, and survivors, the proportion of those who escaped, delayed, or survived the entire 6 years of observation in long-term care was 33.4%/40.4%/26.2% in centenarians, 45.0%/45.1%/9.9% in nonagenarians, and 62.7%/33.7%/3.6% in octogenarians. Age, hospital admissions, and dementia were positively associated with being in long-term care, while musculoskeletal disorders were negatively associated with long-term care. The association with dementia was significantly weaker in centenarians.

For centenarians, although they are more often in long-term care, the transition rate to long-term care progressed more slowly than the rates of the younger comparison cohorts of oldest old. The high proportion of long stays of centenarians in long-term care facilities require different concepts of long-term care.

This abstract refers to Gellert et al. Long-term care status in centenarians and younger cohorts of oldest old in the last 6 years of life: Trajectories and potential mechanisms. Journal of the American Medical Directors Association. 2018. doi: 10.1016/j.jamda.2018.02.010

Dr. Michael Waller, Annette Dobson, Julie Byles, Peta Forder, Xenia Dolja-Gore, Richard Hockey, and Gita Mishra

Title:

Health and Aged-care service use at the end of life by older Australian women with Dementia.

Abstract:

This paper presents information of how data from the Australian Longitudinal Study on Women's Health and multiple linked data-sources have been used to identify women with dementia, and assess health and aged-care service use in the last two-years of life.

The original study cohort included 12432 women born between 1921-26. Each of these women completed an initial survey in 1996, and this data was linked to hospital admissions, pharmaceutical benefits, aged-care, and cause of death data, to identify women who had a dementia record.

After 20 years of study follow-up, 28% of women had a record of dementia. The largest source of dementia records was the aged-care data, with 75% of dementia records identified from this source. The next most common source was the cause of death data (45%), while hospital data identified 36% of dementia records. Sixty per cent of women had their record of dementia identified from more than one of the data sources.

An index group of 2043 women who had dementia and died, were matched to the same number of women who had dementia but were still alive 2-years after the index case died. We also compared 2072 women who had dementia and died, to the same number of women who did not have dementia and lived 2-years beyond the index case.

As might be expected the use of aged care services was generally higher in women with dementia compared to women without dementia. The use of permanent residential aged care increased steadily over time especially as the index cases were nearer to their time of death. In the last 2 years of life, 82% of women with dementia who died used permanent residential aged-care. As they moved to a permanent residential facility the women's the use of many other health and support services declined.

Prof. Gabriele Doblhammer

Title:

Dementia and Survival at Extreme Old Ages. A prospective cohort study of health trajectories among German centenarians and nonagenarians using health claims data.

Abstract:

Whether centenarians and nonagenarians, the fastest growing age groups in high-income countries, will pose a severe burden for societies depends foremost on their physical and cognitive health. We explore whether dementia, major chronic diseases, and diseases related to quality of life are compressed into the last year of life among long-lived individuals by using a large, nationally

representative sample of Germany's biggest health insurer. We followed the 1908-1913 birth cohorts from age 95 to 100 (n=2,865 individuals and 2,397 deaths), and the 1918-1923 birth cohorts from age 85 to 90 (n=17,013 individuals and 8,417 deaths) to analyze disease trajectories in relation to age and age at death. Furthermore, we assess the association of suffering from dementia and other conditions with surviving to the 100th and the 90th birthday by estimating Cox proportional hazard models. Among all diseases dementia and heart disease were special in terms of the advantage of centenarians and nonagenarians: Centenarians, who, at age 95, started with 28 (95% CI: 24-32) dementia cases per 100 population reached 54 cases at age 100. At age 95, among those who died at age 95 the prevalence was 55 cases (95% CI=52-59); at the same age it was 43 cases (95% CI: 37-49) among those who died at age 99. In the multivariate analysis of the older cohort, dementia dominated the risk of dying before age 100 with a hazard ratio (HR) of 1.66 (95% CI: 1.53-1.81). Results were even stronger for the younger cohort.

For most diseases, at the same age, those living longer had a lower prevalence than those who died. Our study suggests that survival at these high ages first of all depends on the presence of dementia with heart disease and pneumonia playing an important role as immediate causes of death.