

Social inequalities in life expectancy and mortality in people with dementia in the United Kingdom

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Abstract

Introduction: Inequalities in life expectancy and mortality by social deprivation in the general population of the United Kingdom are widening. For people with dementia, data on potential gradients in life expectancy and mortality by social deprivation are sparse. This study aimed to explore potential differentials in life expectancy and mortality in people with dementia according to social deprivation.

Methods: Using The Health Improvement Network (THIN) primary care database, we included people with a diagnosis of dementia in the United Kingdom in 2000-2016 and obtained data on age at death and mortality. Comparisons were made according to social deprivation quintiles adjusting for age at diagnosis.

Results: Among 166,268 people with dementia there were no differences in life expectancy and mortality in the most deprived compared with the least deprived. This pattern has been stable during the study period, as no increasing inequalities in life expectancy and mortality according to social deprivation were found.

Discussion: Contrary to the general population, there were limited inequalities in life expectancy and mortality according to social deprivation for people with dementia.

Key words

Dementia; Social deprivation; Social inequality; United Kingdom; Family practice

Introduction

The reduction or elimination of health inequalities has become an increasingly prominent policy target in developed countries in recent years as pervasive and systematic inequalities in health have been documented¹⁻³.

Substantial inequalities in life expectancy and mortality related to social deprivation have been found in the United Kingdom (UK), regardless of underlying diagnosis, with more deprived areas having higher mortality compared with less deprived areas^{4,5}. Moreover, studies suggest that although overall mortality in the UK has been reduced over the past years, inequalities in life expectancy and mortality by social deprivation have widened because of slower mortality declines in the most deprived⁶⁻⁸.

Inequalities in terms of health status and quality of healthcare in people with dementia are evident⁹⁻¹¹, and individuals from the most deprived areas are expected to have shorter life compared with individuals from the least deprived areas¹¹.

In contrast to the overall national mortality rates in the UK, which have decreased over the past years, especially for individuals between 55-89 years of age, mortality rates for people with dementia have increased in recent years^{8,11}. The fact that an increased number of people are dying with a diagnosis of dementia, may be explained by increased reporting of deaths from dementia, including a better understanding of the disease, improved diagnostic awareness and updates in cause of death coding. Furthermore, as people live longer and survive other illnesses, the number of people developing dementia will increase.

Still, knowledge on potential gradients in life expectancy and mortality according to social deprivation over the past years is warranted for people with dementia.

The aim of this study was to examine potential differences in life expectancy and mortality in people with dementia according to social deprivation and whether this has changed from 2000 through 2016.

We aimed to benchmark this against life expectancy and mortality in the general population according to social deprivation in the 2000-2016 period.

Methods

Study design and setting

In this cohort study, we examined UK primary care data obtained from The Health Improvement Network (THIN) primary care database. We included patient records for those who were permanently registered in general practises that met the criteria for acceptable mortality recording and acceptable computer usage from 1 January 2000 to 31 December 2016^{12 13}. A practice's mortality records are deemed complete in the year of acceptable mortality recording and onwards, which ensures mortality recordings in THIN to be near the expected national rate, removing under-reporting of death¹².

Acceptable computer usage is defined as the year in which a general practice continuously enters on average a minimum of two therapy records per patient per year¹³. Within the cohort, we identified people with a diagnosis of dementia.

Data source

We used data from THIN database, because it is one of the largest sources of continuous primary care data in the UK, and because it is broadly representative of the UK population¹⁴. The database covers more than 500 general practices across the UK that have signed up to contribution of the database, and it includes more than 12 million patients. Approximately 98% of the population in the UK are registered in a general practice¹⁵.

Routine consultations by general practitioners are recorded by the hierarchical Read coding system which covers more than 100,000 codes, including diagnoses^{16 17}. In this way, THIN contains a computerised medical record for each patient from the time they register in a general practice. The database also holds information on patients' year of birth, gender, date of registration, date of death and transfer out of practice.

For each patient there is also a measurement of social deprivation described by the Townsend Score, which is a composite measure of the social and economic deprivation of a locality linked within the general practitioner software to each patient's postcode and based on the census data information on

housing, car ownership and employment^{18 19}. In THIN, the Townsend Score is linked to the data from the UK national 2011 census, defined for small areas of around 150 households and grouped into quintiles where the most affluent areas are assigned a score of one and the least affluent a score of five. Quintiles of Townsend Score have been used to study death rates by social deprivation to ensure generalisability of THIN data, and the death rate reports in THIN have been externally validated by comparison with national death rates¹⁴. Thereby the representativeness of the observations by findings of increased mortality by increased social deprivation and decreased overall mortality for different levels of social deprivation over the years have been documented¹⁴. In this way, social deprivation according to Townsend Score could serve as an important tool for documenting social inequalities in health status and for monitoring trends in the extent of inequality over time for people with dementia. The diagnoses of dementia made by general practitioners recorded in UK primary care databases have been validated and confirmed in 83% of the cases²⁰. However, previous studies showed that dementia tends to be under-recorded in general practice records, and that general practitioners tend to seek specialist advice before making the diagnosis of dementia, because they do not feel skilled enough themselves²¹. This may suggest that the diagnosis of dementia in general practice records has low sensitivity but high specificity.

The recording of death within THIN has been validated and found correct in 99% of the cases²².

People with dementia

Life expectancy

For the study of life expectancy, we included adults aged 50 years or over with either a prevalent or an incident diagnosis of dementia in the period 1 January 2000 to 31 December 2016, identified by extraction of medical records and prescriptions from 1 January 1995 to 31 December 2016.

We developed lists of Read codes to identify recorded first ever diagnoses (codes for Alzheimer's disease, vascular dementia, senile dementia, dementia with Lewy bodies, frontotemporal dementia, alcoholic dementia and dementia in other diseases, including Pick's disease, Creutzfeldt-Jakob

disease, Huntington's disease and Parkinson's disease) and codes to identify all records with a mention of dementia (codes for monitoring of dementia, dementia care plan, dementia annual review and history of dementia). In addition we identified patients who received anti-dementia medication, including memantine or cholinesterase inhibitors as sometimes individuals may receive anti-dementia medication before they have a diagnosis of dementia in their primary care records. We retrieved data on age at diagnosis using THIN database and divided the cohort into age groups.

Mortality

For the mortality study, we included adults aged 50 years or over with a first ever code for dementia during the period 1 January 2000 to 31 December 2016.

Statistical methods

All statistical analyses were performed using Stata 14 software (StataCorp.2015. *Stata Statistical Software: Release14*. College Station, TX: StataCorpLP), and they were made separately for men and women.

Dementia diagnosis rates

We examined the recorded dementia diagnoses within the 2000-2016 period, calculating dementia diagnosis rates as the number of new diagnoses divided by the total number of person years of follow-up in the general population. These were estimated according to quintiles of the Townsend Score and age groups and stratified to make annual dementia diagnosis rates by social deprivation.

Life expectancy

For the study of life expectancy by social deprivation, within the cohort of people with a prevalent or incident diagnosis of dementia, we estimated mean age at death. We excluded individuals who transferred out of their practice as well as those being in practices that stopped contributing data to

THIN. We did this after conducting analyses showing that the number of individuals excluded were small and equally distributed in number and mean age between Townsend quintiles, calendar years of death and age at diagnosis for men and women, respectively.

Mean age at death was calculated by categories of social deprivation according to quintiles of the Townsend Score. This was done for the entire study period, and additionally, stratified to make annual mean age at death by social deprivation for each calendar year. Subsequently, the mean age at death according to social deprivation was graphed by calendar year of death.

As we were working with population data, we used a Poisson regression model to compare the mean age at death between individuals in the least deprived quintile through the most deprived quintile, calculating relative age at death adjusted for age at diagnosis, using the least deprived as the reference category. In secondary analyses, we also made adjustments for age at diagnosis and calendar year. Additionally, we carried out all analyses of adjusted relative age at death while clustering by practice, but this showed similar results.

In order to benchmark our estimates of life expectancy, we repeated the analyses using the general population as study population.

Mortality

For the study of mortality within the cohort of people with a first ever diagnosis of dementia, individuals were followed up from their first diagnosis or their first prescription of anti-dementia medication.

Mortality rates were calculated as number of deaths divided by the total number of person years of follow-up. People with dementia started contributing to person years at risk the latest of study start date, registration date, date for acceptable mortality recording and date for acceptable computer usage. Similarly, they stopped contributing to person years at risk at the earliest of study end date, date of death, date transferred out of practice and date of last registration.

Mortality rates were calculated by categories of social deprivation according to Townsend quintiles. This was done for the entire study period, and, additionally, stratified to make annual mortality rates by social deprivation. Subsequently, mortality rates according to social deprivation were graphed by calendar year of death.

A Poisson regression model was used to compare the mortality rate of individuals in the least deprived quintile through the most deprived quintile. Thus, calculating mortality rate ratios adjusted for age at diagnosis, using the least deprived as the reference category. In secondary analyses, we also adjusted the mortality rate ratios for age at diagnosis and calendar year of death. When clustering by practice, similar results were shown.

We repeated all analyses using the general population as study population.

Results

We identified 651 practices that met the criteria for acceptable data recording in the 2000-2016 period including a source population of 3,332,416 people. In total, 166,268 people either had a prevalent or incident diagnosis of dementia, and 148,595 people had a first ever diagnosis of dementia recorded in THIN database in the study period (Table 1).

Dementia diagnosis rates

During 2000-2016, the dementia diagnosis rate increased for both men and women regardless of deprivation quintile from 2.1 (95% CI: 2.0; 2.3) to 3.9 diagnoses per 1000 person years (95% CI: 3.7; 4.0) for men and from 3.4 (95% CI: 3.2; 3.6) to 5.3 diagnoses per 1000 person years (95% CI: 5.1; 5.5) for women. The increase was especially pronounced in the oldest age groups (60-90 years).

The gradient of this increase in diagnosis rate according to calendar years of death was almost the same for all quintiles of deprivation during the 2000-2016 period, especially evident among women from Townsend quintile five (data not shown).

Life expectancy

Among people with either a prevalent or incident diagnosis of dementia, the mean age at death for men in 2000-2016 ranged from 83.0 years (95% CI: 82.7; 83.3) in people from Townsend quintile five (the most deprived) to 84.2 years (95% CI: 84.0; 84.4) in people from Townsend quintile two (the second least deprived). Similarly, the mean age at death for women ranged from 86.5 years (95% CI: 86.3; 86.7) in people from Townsend quintile five to 87.7 years (95% CI: 87.6; 87.8) in people from Townsend quintile two (Table 2). Correspondingly, the adjusted relative age at death when compared with the least deprived did not show any differences between quintiles of social deprivation (Table 2). During the 2000-2016 period, life expectancy increased for both men and women regardless of deprivation quintile (Figure 1). The gradient of this increase in mean age at death according to calendar years of death was almost the same for all quintiles of deprivation during 2000-2016. Correspondingly, the adjusted relative age at death was 1.00 for all deprivation quintiles when compared with the least deprived within each calendar year (see Table, Supplemental Digital Content (SDC) 1, showing mean age at death and adjusted relative age at death).

For the general population, the difference in life expectancy according to quintiles of social deprivation varied more than that for people with dementia. The mean age at death for men ranged from 75.4 years (95% CI: 75.3; 75.5) in people from Townsend quintile five to 78.6 years (95% CI: 78.5; 78.7) in people from Townsend quintile two, whereas for women this was 80.5 years (95% CI: 80.4; 80.6) to 83.1 years (95% CI: 83.0; 83.2) (Table 2).

In addition, this gap in life expectancy according to social deprivation seemed to widen during the 2000-2016 period, due to an increase in mean age at death in the least deprived concurrently with virtually no changes in mean age at death in the most deprived. Hence, the mean age at death went from 76.5 (95% CI: 76.0; 77.0) to 79.8 years (95% CI: 79.4; 80.3) in men from Townsend quintile one, and from 81.3 (95% CI: 80.8; 81.7) to 83.2 years (95% CI: 82.7; 83.7) for women from Townsend

quintile one, but remained unchanged for men and women from Townsend quintile five, respectively, in the 2000-2016 period (Figure 1)(see Table, SDC 1).

Mortality

Among people with a first ever diagnosis of dementia, men from Townsend quintile five had the lowest mortality rate by 137.4 deaths per 1000 person years (95%CI: 131.8; 143.1), whereas men from Townsend quintile three had the highest mortality rate by 146.8 deaths per 1000 person years (95%CI: 142.6; 151.1) (Table 3). Correspondingly, the mortality rate for women was lowest in Townsend quintile five by 118.7 deaths per 1000 person years (95%CI: 115.1; 122.4) and highest in Townsend quintile two by 129.9 deaths per 1000 person years (95%CI: 127.2; 132.5). However, the corresponding adjusted mortality rate ratio showed small variation according to social deprivation quintiles for both men and women (Table 3).

During the 2000-2016 period, mortality increased for both men and women regardless of deprivation quintile. In addition, the mortality rates for men revealed a tendency of a widening gap according to social deprivation during 2000-2016 (Figure 2). However, this gap was narrowed in the adjusted mortality rate ratios accounting for age at diagnosis (see Table, SDC 2, showing mortality rate and adjusted mortality rate ratio).

For the general population, the difference in mortality according to quintiles of social deprivation varied more than for those individuals diagnosed with dementia. Mortality rates for men ranged from 16.0 per 1000 person years (95%CI: 15.8; 16.1) in people from Townsend quintile one to 27.2 per 1000 person years (95%CI: 26.9; 27.5) in people from Townsend quintile five. For women this ranged from 16.1 (95%CI: 15.9; 16.2) to 27.5 per 1000 person years (95%CI: 27.2; 25.8) (Table 3). The corresponding adjusted mortality rate ratio was 1.64 (95%CI: 1.62; 1.66) in men from Townsend quintile five and 1.37 (1.35; 1.39) in women from Townsend quintile five compared with men and women from Townsend quintile one, respectively (Table 3). In addition, this gap in mortality

according to social deprivation widened during 2000-2016, even after adjusting for age at death and calendar year of death (see Table, SDC 2).

Discussion

In the present study, representative of the entire UK population, we demonstrated little difference in life expectancy and mortality by social deprivation in people with dementia. Though inequalities in life expectancy and mortality according to social deprivation seem to have increased for the general population within the 2000-2016 period, this pattern was not found for people with dementia.

The evidence on mortality associated with socioeconomic status in people with dementia is mixed. Some studies suggest an association between lower socioeconomic status, based on disposable household income, and higher mortality risk in men and women with dementia at any age²³. Yet, other studies have not shown an association between income and mortality risk²⁴⁻²⁶, and an association of educational level and occupation and the risk of mortality has not been indicated either^{25 27-31}.

A previous UK study has shown that people with dementia are treated differently according to social deprivation, i.e. the least deprived were 25% more likely to get anti-dementia medication prescribed compared with the most deprived¹⁰. There is no evidence that anti-dementia medication is life prolonging, but it is often contraindicated in frail people, e.g. with recurrent falls or specific cardiac diseases, and more likely to be prescribed in people who have live-in caregivers. These factors may lead to lower mortality in people prescribed anti-dementia medication. Our results, however, do not suggest that this difference in treatment with more anti-dementia medication prescribed for the least deprived has an effect on life expectancy and mortality.

Instead, we observed an effect of age at time of dementia diagnosis, since this seemed to level out the small difference in life expectancy and mortality according to social deprivation in our age at diagnosis adjusted analyses. This may be explained by the fact that more educated people have a

longer time to diagnosis of dementia, because the impact of pathology on clinical expression of dementia may be mitigated but then have faster cognitive decline than those with lower cognitive reserve ^{32 33}.

Among people with dementia, it has been suggested that the most disadvantaged regarding quality of vascular care in UK general practice seemed to be individuals with the fewest comorbid physical conditions ³⁴. Since the number of comorbidities for people with dementia presumably increase with increasing level of deprivation as for the general population, the most deprived people with dementia have more comorbid conditions and may, therefore, be devoted more attention in general practice ³⁵. This could explain the slightly higher mortality in the least deprived people with dementia found in the present study, as their overall health may not be monitored to the same extent as for the most deprived. For the general population, however, it is well-known that the most deprived receive lower quality of primary care ³⁶, which may explain our findings of higher mortality and lower life expectancy in the most deprived.

The main strengths of our study include its size and length of follow-up, and that the results are generalizable to people with dementia in the UK, due to the representativeness of THIN database. Using THIN data, we only included individuals who had the diagnosis of dementia coded in their primary care record. It has been found that dementia is underdiagnosed by general practitioners and that many individuals with suspected dementia or symptoms of dementia do not get a diagnosis of dementia recorded in their primary care record ¹⁵.

THIN data are registered prospectively without knowledge about the various outcomes of the current study, and in UK primary care databases, 83% of the recorded diagnoses of dementia made by general practitioners have been confirmed ²⁰. Moreover, death rate recordings in THIN database according to quintiles of the Townsend Score are valid ¹⁴.

THIN data give some limitations to the study as these cannot provide detailed information on severity of illness, comorbid conditions, life style factors, social support network, formal level of care etc.

according to social deprivation. Therefore, our results may have been confounded by these unmeasured factors, not available in the current study, and residual confounding.

Around one third of deaths with a recorded mention of dementia have additional recorded comorbidities in terms of respiratory disease (38% of dementia deaths) or circulatory disease (36% of dementia deaths)¹¹. However, it is not known whether these comorbidity patterns differ according to social deprivation and it has been suggested that recorded comorbidities for people with dementia are incomplete³⁷. This may be explained by the fact that people with dementia may be less likely to be fully investigated than other people with chronic diseases. Yet, for the general population, the number of comorbidities increase with increasing deprivation, and this may be the same for people with dementia³⁵. However, age, the strongest risk factor for dementia, was equally distributed by social deprivation in the present study. Therefore, we cannot rule out that our results of slightly lower mortality in the most deprived are not biased by survival, since individuals who have more competing illnesses, including comorbidities, and survive them long enough to develop dementia, may be more robust and have lower mortality.

In a subsequent analysis, we examined the recorded dementia diagnoses within the 2000-2016 period. This analysis indicated a substantial increase in the recorded dementia diagnosis during 2000-2016, especially evident in the oldest age groups (60-90 years). We do not know if this was caused by an increase in actual dementia incidence or by an increase in the identification incidence of people with dementia of which the UK National Dementia Strategy in 2009 was a big policy driver³⁸. Since the increase in recorded dementia diagnoses in THIN data were mostly recognised in the oldest of age groups, it may indicate, that more patients die with a recorded diagnosis of dementia now compared with previously. Thus, this may at least partly be accounted for by including age at diagnosis in the adjusted analyses.

The present study does not allow us to determine whether the observed findings of limited inequality in life expectancy and mortality according to social deprivation for people with dementia reflect appropriate provision of care nor whether this were congruent with preferences of patients and

families. Still, the findings warrant consideration, since the diagnosis of dementia seemed to level out the effect of social inequalities which were found in the general population. In this way, patients diagnosed with dementia seemed to have a similar course of disease, regardless of socioeconomic status. Yet, the likely survival bias in the most deprived, raise the question of what may be making those individuals more robust in order to understand why they can overcome the effects of lower socioeconomic status, surviving more competing illnesses, compared with the less deprived, long enough to be diagnosed with dementia. More extensive information will be required in order to clarify these important issues.

Among people with dementia, there was less inequality in life expectancy and mortality according to social deprivation, and it remained stable during the 2000-2016 period. This was contrary to the general population, in which there were substantial increasing differences with most deprived having a considerably lower life expectancy and higher mortality compared with the least deprived.

To ensure appropriate planning of health and social care, including palliative care, for people with dementia, further understanding of the mechanisms of social inequality is needed.

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Figure legends

Figure 1: Age at death for people with dementia and for the general population, respectively.

Figure 2: Mortality rate for people with dementia and for the general population, respectively.

Supplemental Digital Content

Supplemental Digital Content 1.docx

Supplemental Digital Content 2.docx