Linkage of national health and social care data: a cross-sectional study of multimorbidity and social care use in people aged over 65 years in Scotland.

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Keywords: Social Care , Multimorbidity , Data Linkage , Long-term care ; older people. **Key points:**

- This is the first study to link health and social care data at a national level
- We find an empirical link between receipt of social care and multimorbidity
- Those living in more deprived areas are more likely to receive social care
- No useful measure of social care need is collected nationally
- There are difficulties measuring multimorbidity and frailty on a national scale

Abstract

Background

Little is known about the relationship between multimorbidity and social care use (also known as long-term care). The aim of this study was to assess the relationship between receipt of formal social care services and multimorbidity.

Methods

This retrospective data linkage, observational study included all individuals over the age of 65 in the population of Scotland in financial years 2014/15 and 2015/16 (n= 975,265). The main outcome was receipt of social care measured by presence in the Scottish Social Care Survey. Logistic regression models were used to assess the influence of multimorbidity, age, sex, and socioeconomic position on the outcome reporting Average Marginal Effects (AME).

Findings

93.3% of those receiving social care had multimorbidity. 16.2% of those with multimorbidity received social care compared to 3.7% of those without. The strongest magnitudes of AME for receiving social care were seen for age and multimorbidity (respectively 50% and 18% increased probability comparing oldest to youngest and most severe multimorbidity to none). A 5.5% increased probability of receiving social care was observed for the most-deprived compared to the least-deprived.

Interpretation

Higher levels of social care receipt are observed in those with increasing age, severe multimorbidity and living in more deprived areas. Multimorbidity does not fully moderate the relationship between social care receipt and either age or deprivation.

Introduction

Background and objectives

Routinely referred to as social care in the UK, long-term care describes a range of services that can be provided at home, in institutions, or via cash benefits comprising assistance with personal care activities of daily living (ADL), often in combination with nursing care, and/or instrumental activities of daily living (IADL) such as domestic help [1].

Little is known about the relationship between multimorbidity and social care. Over two-thirds of those receiving social care in Scotland are over the age of 65 years [2] whilst approximately two-thirds of all those over the age of 65 years have multimorbidity [3]. It

would seem intuitive that a large proportion of those receiving social care have multimorbidity but there is no empirical evidence of this.

In Scotland, social care services are provided or funded by 32 local authorities. Since 2002, in contrast to other parts of the UK, personal and nursing care have been provided free in the community to those assessed as eligible [4]. This means there are fewer individuals who entirely self-fund their care and are absent from administrative records.

The Social Care Survey (SCS), collected by the Scottish Government, contains individual-level data from each local authority detailing the types and amounts of social care they provide with recent probabilistic data linkage enabling matching to health data on a national scale [5]. Combined with the provision of Free Personal and Nursing Care (FPNC), this ability to link data means unique analyses regarding health and social care are now possible with Scottish data. The aim of this study is to assess the association between receipt of formal social care services, multimorbidity, age, sex, and socioeconomic position (SEP).

Methods

Study design and setting

We conducted a retrospective observational study for all people over the age of 65 in Scotland for the financial years (1st April – 31st March) 2014/15 and 2015/16. Reporting follows the protocol laid down in the Reporting of studies using observational routinely collected health data (RECORD) statement [6].

Approval for this study was granted by the Public Benefit and Privacy Panel for health and social care (Ref: 1617-0304/Henderson). Approval from this panel is mandatory in order to access anonymised person-level data for research purposes. The method of approval and access to data in this fashion has been described more extensively elsewhere [7].

Participants

Individuals were identified from the Community Health Index (CHI) database held by the Information Services Division (ISD) of NHS National Services Scotland. This database contains records of anyone who was born, registers with a GP, or who dies in Scotland and is used operationally for transferring GP records. The study population included all those born before 31st March 1954 and still alive between 1st April 2014-31st March 2016 and therefore over the age of 65 during the study period. Records from the smallest mainland local authority (1% total population ~10,000 individuals) were removed due to low linkage rates to the SCS.

A diagram showing the process of linkage between databases is shown in Appendix 1.

Variables

The main outcome measure of the study was receipt of social care (defined below). Independent variables were: age, sex, SEP (measured by the 2012 iteration of the Scottish Index of Multiple Deprivation (SIMD) decile of residence) [8], and a measure of multimorbidity (defined below). Rendered R markdown workbooks of all code used to clean data, classify variables, and complete analysis are available in Appendix 2.

Data sources/measurement

Social care receipt

Receipt of social care was measured by presence or not in the SCS which has been fully described elsewhere including definitions of FPNC and other service types [5]. In brief, information on all individuals who have a social care assessment and go on to receive or use: home care, FPNC, meals, housing support, community alarm, telecare, self-directed support, or social worker/support worker services are included. The home care element of the return is based on those receiving this service during a census week – usually including the 31st of March. Other elements reflect individuals receiving care at any time in the financial year [5].

Multimorbidity

In order to assess the effect of multimorbidity on receipt of social care, a measure that could be applied to the entire population was required. Past research [9, 10] has shown a count of prescribed medicines to be as good a predictor of healthcare use and mortality as other more complex indices and a useful proxy measurement for multimorbidity. The Scottish Prescribing Information System (PIS) [11] offers a comprehensive source of data regarding all community prescriptions in Scotland.

A count of the number of different medicines prescribed in each financial year was created. To be included in the count, a medicine had to be prescribed in more than one quarter of each financial year (or for those that died in the first quarter of each year, just that quarter).

The list of eligible medicines for inclusion in the count was derived from a modified version of the table provided in supplementary material by Guthrie et al [12]. This list omits medicines that do not deliver drugs (e.g. monitoring equipment, dressings etc.) as well as vaccines and drugs used in anaesthesia.

Individuals were classed as having multimorbidity if they were prescribed medicines from two or more BNF chapters.

Demographics

Demographic variables were derived from the CHI central register and included, sex (male/female), month and year of birth, month and year of death, and SIMD decile of residence.

Multiple time periods for addresses were provided for participants who moved during the study period. SIMD status was allocated by the most recent address available during the financial year.

Bias

Individuals resident in a care home were omitted from the main analysis as, although possible to be included in the SCS, they represent a distinct population with different care needs from those under consideration in this study. For comparison, three additional models were run. One including the individuals from care homes, one dropping those that died during each financial year of data, and a third using an alternative measure of multimorbidity – a grouped count of prescribed repeat medicines. These sub-analyses are reported in Appendix 2.

Statistical methods

We used logistic regression models with receipt of social care as the binary outcome measure with independent variables as outlined above. Main analyses are reported with a count of BNF chapters as the main proxy multimorbidity measurement (as a crude indication of the number of body systems treated). Two models were fitted, one to each financial year of data. Interaction terms were fitted between age group and BNF chapters as well as between SIMD decile and BNF chapters, therefore we report Average Marginal Effects (AMEs) as opposed to odds-ratios or class probabilities [13]. Model fit was assessed using McFadden's pseudo-R² statistic where values of 0.2-0.4 are taken to indicate excellent fit [14]. All analyses were conducted using the R language and environment for statistical computing version 3.6.1 [15]. AMEs were calculated with standard errors and 95% confidence intervals using the R package "margins" [16] version 0.3.23. A full list of software packages utilised is available in Appendix 2.

Linkage

Linkage of the SCS to CHI was conducted by analysts from the National Records of Scotland and has been described more fully elsewhere [5]. Excluding the smallest mainland local authority due to an exceptionally low linkage rate, a 91% match rate to CHI for those present in the SCS was achieved with no bias seen across age, sex, or deprivation

categories. Large variation in match rate was present at the local authority level which made comparison across councils impossible due to the risk of introducing bias.

Results

Participants and descriptive data

Characteristics of the total population and split by multimorbidity status were similar across both years of data in the main analysis. Counts and percentages of those in financial year 2015/16 are shown in Table 1. A total of 897,695 individuals were included in this year, of which 74% had multimorbidity. Compared to the overall population, a higher percentage of those that were: female, older, more deprived, and receiving social care had multimorbidity. In the 26% of the population without multimorbidity, a clear gradient in the percentage of people living in each SIMD decile is observed.

Table 1 – Characteristics of population by multimorbidity status 2015/16

| | | Total | With multimorbidity | Without multimorbidity |
|--------------|---------------------|---------------|---------------------|------------------------|
| | | (n=897,695) | (n=664,375) | (n=233,320) |
| Sex | Male | 408264 (45.5) | 291393 (43.9) | 116871 (50.1) |
| | Female | 489431 (54.5) | 372982 (56.1) | 116449 (49.9) |
| Age group | 65-69 | 281482 (31.4) | 176703 (26.6) | 104779 (44.9) |
| | 70-74 | 214070 (23.8) | 153712 (23.1) | 60358 (25.9) |
| | 75-79 | 171901 (19.1) | 136747 (20.6) | 35154 (15.1) |
| | 80-84 | 124601 (13.9) | 105578 (15.9) | 19023 (8.2) |
| | 85-89 | 70736 (7.9) | 61331 (9.2) | 9405 (4.0) |
| | 90-94 | 27930 (3.1) | 24327 (3.7) | 3603 (1.5) |
| | 95 plus | 6975 (0.8) | 5977 (0.9) | 998 (0.4) |
| SIMD decile | 1 - most deprived | 74688 (8.3) | 61079 (9.2) | 13609 (5.8) |
| of residence | 2 | 82379 (9.2) | 66100 (9.9) | 16972 (7.0) |
| | 3 | 92227 (10.3) | 73233 (11.0) | 18994 (8.1) |
| | 4 | 94247 (10.5) | 72673 (10.9) | 21574 (9.2) |
| | 5 | 95382 (10.6) | 71415 (10.7) | 23967 (10.3) |
| | 6 | 97095 (10.8) | 70178 (10.6) | 26917 (11.5) |
| | 7 | 92549 (10.3) | 64972 (9.8) | 27577 (11.8) |
| | 8 | 89828 (10.0) | 63025 (9.5) | 26803 (11.5) |
| | 9 | 90323 (10.1) | 62631 (9.4) | 27692 (11.9) |
| | 10 - least deprived | 88977 (9.9) | 59069 (8.9) | 29908 (12.8) |
| Receiving | Yes | 116130 (12.9) | 107493 (16.2) | 8637 (3.7) |
| Social Care? | No | 781565 (87.1) | 556882 (83.8) | 224683 (96.3) |

All values show n(%)

Outcome data

There were higher proportions of: women, older people, those living in more deprived SIMD deciles, and with more severe multimorbidity receiving social care (Table 2). For example, 66.5% of those receiving social care in 2015/16 were women whereas the overall percentage of women in the population was 54.5%. Similarly, the percentage of those receiving social care and classified as having multimorbidity was 93.3% where the overall level of multimorbidity in the population was 74.3%. Visualising the percentage of those that receive social care at specific ages (Figure 1), reveals an increase with age that is disproportionately biased towards those that are female, with lower SEP, and higher severity of multimorbidity.

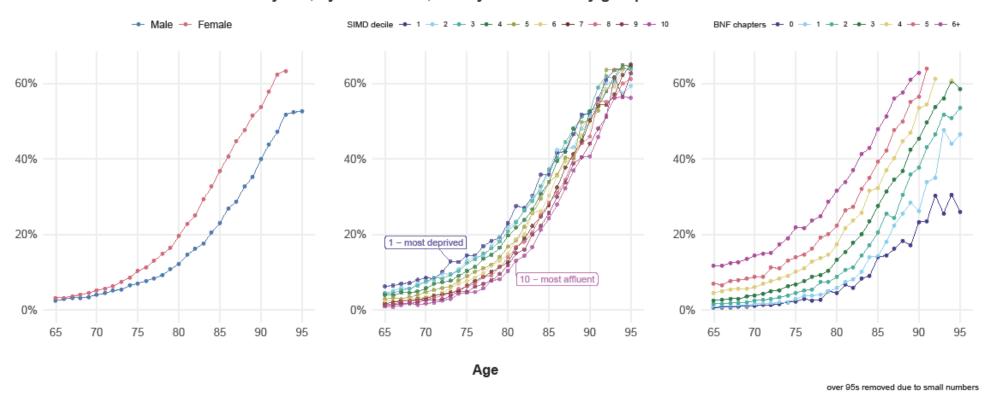
Table 2 - receipt of social care 2015/16

| | | Total | No Social Care | Social Care |
|--------------|--------------------|---------------|----------------|--------------|
| | | (n=897,695) | (n=781,565) | (n=116,130) |
| Sex | Male | 408264 (45.5) | 369333 (47.3) | 38931 (33.5) |
| | Female | 489431 (54.5) | 412232 (52.7) | 77199 (66.5) |
| Age group | 65-69 | 281482 (31.4) | 271316 (34.7) | 10166 (8.8) |
| | 70-74 | 214070 (23.8) | 200775 (25.7) | 13295 (11.4) |
| | 75-79 | 171901 (19.1) | 151789 (19.4) | 20112 (17.3) |
| | 80-84 | 124601 (13.9) | 97070 (12.4) | 27531 (23.7) |
| | 85-89 | 70736 (7.9) | 44254 (5.7) | 26482 (22.8) |
| | 90-94 | 27930 (3.1) | 13525 (1.7) | 14405 (12.4) |
| | 95 plus | 6975 (0.8) | 2836 (0.4) | 4139 (3.6) |
| SIMD decile | 1 – most deprived | 74688 (8.3) | 61782 (7.9) | 12906 (11.1) |
| of residence | 2 | 81292 (9.2) | 68213 (8.8) | 13079 (11.3) |
| | 3 | 90541 (10.2) | 75669 (9.8) | 14872 (12.9) |
| | 4 | 92323 (10.4) | 78652 (10.2) | 13671 (11.8) |
| | 5 | 94417 (10.6) | 81933 (10.6) | 12484 (10.8) |
| | 6 | 96064 (10.8) | 84447 (10.9) | 11617 (10.1) |
| | 7 | 92220 (10.4) | 81857 (10.6) | 10363 (9.0) |
| | 8 | 89336 (10.1) | 79741 (10.3) | 9595 (8.3) |
| | 9 | 90133 (10.2) | 81187 (10.5) | 8946 (7.7) |
| | 10 – most affluent | 88603 (10.0) | 80241 (10.4) | 8362 (7.2) |
| Total BNF | 0 | 99737 (11.2) | 97228 (12.6) | 2509 (2.2) |
| chapters | 1 | 128722 (14.5) | 123505 (16.0) | 5217 (4.5) |
| | 2 | 153230 (17.4) | 141958 (18.6) | 11272 (9.8) |
| | 3 | 151091 (17.2) | 133291 (17.4) | 17800 (15.5) |
| | 4 | 130414 (14.8) | 108731 (14.2) | 21683 (18.8) |
| | 5 | 97657 (11.1) | 76382 (10.0) | 21275 (18.5) |
| | 6+ | 121460 (13.8) | 86374 (11.3) | 35086 (30.5) |

All values n(%)

Figure 1

Percentage of individuals at specific ages receiving any form of social care by sex, by SIMD decile, and by multimorbidity group. 2015/16



Main results

Models fitted to data from 2014/15 and 2015/16 showed similar results (Figure 2 and tables in Appendix 2). After adjustment for all independent variables specified above, AMEs show that the probability of receiving social care increased with severity of multimorbidity. In 2015/16, the increased probability of receiving social care compared to those receiving no prescribed medicines was 1.2%, 3.3%, 6.0%, 9.4%, 12.7%, and 18.6% for those receiving prescribed medicines from 1, 2, 3, 4, 5, and 6 or more BNF chapters respectively.

Age showed the largest magnitude of adjusted AMEs where effects increased from 2.2% in age-group 70-74 to almost 50% increased probability of receiving social care in age-group 95-plus compared to age-group 65-69.

The adjusted AME for SEP was lower than seen for age and multimorbidity status with those in the most deprived SIMD decile having a 5.5% increased probability of receiving social care compared to those in the most-affluent decile. Women had a 3.2% increased probability of receiving care than men.

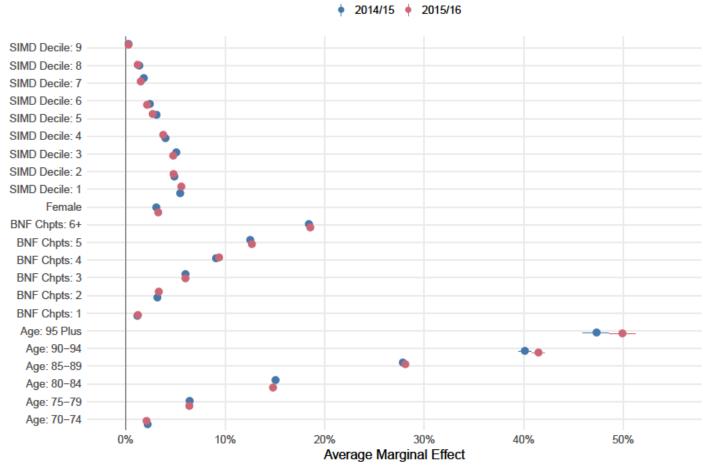
McFadden's pseudo-R² statistic was 0.206 for the model fitted to data from 2014/15 and 0.217 for 2015/16 (Appendix 2) indicating models had an excellent fit to the data.

Other analyses

Three sub-analyses were conducted using a) a different measure of multimorbidity using a count of repeat medicines as opposed to BNF chapters, b) all available observations i.e. including those living in care homes, and c) a subset of data omitting all those that died in each financial year. Notably, little difference in results was observed across sub-analyses. The grouped count of repeat prescribed medicines had similar AMEs but with a sharper gradient indicating the smaller number of groups. Goodness-of-fit statistics also showed little change for all sub-analyses. All results are available in Appendix 2.

Figure 2

Influence of variables on receiving social care



Ref group SIMD: Decile 10 Ref group BNF Chpts: 0 Ref group Age: 65-69

Discussion

This is the first study to link individual-level health and social care data on a national scale. It shows that multimorbidity is associated with receipt of social care. This is a novel finding and has important implications given the increasing prevalence of multimorbidity and recent reductions in the provision of social care services in the UK [17-19]. This is particularly true given our finding that increasing age is also strongly associated with receipt of care after adjustment for multimorbidity, sex, and deprivation status.

To our knowledge, this is the first analysis of the assessment of receipt of social care by SEP at a national level. Higher levels of social care receipt are found in people with higher deprivation, with effects remaining after adjustment for other factors. However, no good measure of social care "need" is available for analysis meaning robust conclusions cannot be drawn about the adequacy of service levels for the most disadvantaged groups. Given the ongoing existence of the inverse care law in primary care provision in the UK [20, 21], the question of a parallel inverse social care law remains unknown.

Our results show females are more likely to receive social care than males. However, this could potentially be explained by higher levels of women surviving their partners and therefore being more likely to live alone – an important variable unavailable in the linked datasets.

Social care services not included in the FPNC package, such as community alarm and telecare, are subject to charges set by each local authority that are progressively adjusted according to means. Crucially, all those in receipt of these services are captured in the SCS which, despite limitations discussed below, make it a unique resource in research terms.

Limitations

As with all observational research our findings indicate association between variables only and cannot identify causal pathways. Furthermore, unobserved confounding variables could exist and have an influence on the reported effects. Three such unobserved measures include an indicator of living arrangements (i.e. identifying those living alone) and indicators of frailty and of social care need utilising ADLs.

The use of administrative data, whilst offering the opportunity to address previously inaccessible questions, also carries a number of limitations including coverage and measurement [22].

The SCS is a unique source of social care data but does not include every individual that received social care in each year. Details of those receiving home care are collected during a census week only. In 2014/15 and 2015/16, home care accounted for approximately 33% of all services eligible to be included in the SCS [23]. As such, we expect the proportion of misclassification to be small, but cannot fully account for its effects on results.

Lack of access to primary care data meant a proxy measurement of multimorbidity was used. Our choice to include only BNF codes that related to directly delivered medicines meant our measure focussed on clinically relevant prescriptions. Whilst previous research has shown prescribing records are not inferior to other measures of multimorbidity [9, 10], disease data from primary care remains the only source from which to directly assess multimorbidity in the general population.

For the same reason, we were unable to assess receipt of social care by frailty. Whilst an electronic frailty index has been developed [24] and adapted for use in Scotland [25], it also partly relies on Read codes derived from primary care data and was not available during study set-up. As the majority of individuals with frailty also have multimorbidity [26], future work involving social care receipt should include this measure where possible.

Comparison to previous literature

Despite limitations, our study still provides the first large-scale assessment of receipt of social care. One small-scale study in Japan [27] used expenditure on social care services as an outcome and assessed how multimorbidity mediated this. Whilst the specific measures of social care and multimorbidity differed from the present study it is notable that results are similar: increased age and severity of multimorbidity were associated with increased social care expenditures.

Implications

Social care has rarely been investigated in relation to multimorbidity or health care utilisation – partly due to the historical lack of good data. This paper demonstrates that data linkage offers a partial remedy to this situation and highlights important links between multimorbidity and social care use. Rising prevalence of multimorbidity has the potential to result in increasing demand for social care services – a fact of great importance for policymakers internationally.

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