

What can administrative data tell us about caregiving and volunteering? Does helping help the helpers:

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Introduction

The aim of this paper is to illustrate the added value achievable using dynamically linked administrative data sources: to do this by examining in detail a series of studies related to the morbidity and mortality outcomes of caregivers and volunteers in the UK; to show how this data allow novel research questions to be asked and approaches to be derived – for example, in relation to rare health outcomes, or in using the extant data structures to utilise the detail of relationships within families; and lastly, to show how these innovations can generate policy-relevant answers based on robust research. Finally, we review the limitations of the current data, and conclude by making suggestions for improvement in future censuses.

Policy relevance

The studies are thematically linked and focus on prosocial activity - people involved in *volunteering* and *informal caring* (or *caregiving* as it is more often called). Given what may be a developing crisis in social care at the UK national level, these activities are increasingly being advocated or relied upon by government to provide a voluntary system of care – something that in itself puts research of this type at the heart of policy relevance. The term *informal caregiving* describes those who provide (without pay) care or assistance to people who are ill or need help with personal activities of daily living. *Volunteering*, according to the UN definition¹, is an activity with at least three elements - it is not primarily for profit; it is undertaken freely; and should benefit others (however, many also limit the activity to organised settings, some exclude help given to family members, and others suggest that *recognition* be an additional defining characteristic). There is therefore some ambiguity in the most widely used definitions of volunteering² and an element of overlapping misclassification with caregiving³ is possible - for example, in the provision of assistance to non-family members, or other types of non-organised helping. One final point to note is that, although similar in that they represent different types of *helping* behaviours, they are perceived very differently by the public, especially in relation to their presumed effects on health.

Methodological approach

In this section we introduce in some detail the questions on *caregiving* (2001 and 2011 UK Censuses) and *volunteering* (2011 Census) and outline their potential as elements in this more dynamic scenario, especially when compared to the more traditional methodologies (for example, general population surveys or specifically targeted surveys). While dedicated surveys allow researchers to customise design features (for example, inclusion of recognised assessment and outcome instruments), they are expensive, resource intensive and can have problems with generalisability either because of the particular population sub-group selected, or some unintended participation bias. Such studies typically record response rates of 60-65% and the idea that those who respond are typically different from those who do not must always be addressed. Additionally, they are typically cross-sectional and it can therefore be difficult to separate cause and effect from amongst the various associations recorded. To contrast: because the data already exists research using administrative data is usually more efficient than commissioned surveys; there is normally no additional respondent burden; and, as administrative datasets include whole populations, findings are more generalizable, robust and facilitate detailed analysis of smaller population sub-groups or geographical patches. Finally, the dynamic structure of routine administrative databases is important - typically they are updated on an ongoing basis or are linkable to other databases, allowing additional newly-formed research questions to be relatively easily examined. However, they don't provide a perfect scenario - the many caveats to accessing, manipulating and analysing administrating data will be described in the course of the paper.

Data sources

The main data source for these studies was the Northern Ireland Mortality Study (NIMS), a record-linkage study comprising the census returns for the whole enumerated population (circa 1.7m people) and subsequently registered deaths. The details of both NIMS and linkage processes are described elsewhere⁴. For most of the studies the population-at-risk comprised all enumerated adults not living in institutional settings, with mortality follow-up for either three or four years from the Census (depending on the timing of the study). All personal characteristics were drawn from the census returns and selected on the basis of their known association with caregiving, volunteering or mortality risk: these include age; gender; and marital status (married, never married, and – as a single group - those widowed, separated or divorced). Religious affiliation was also included where appropriate as religiosity has been associated with both volunteering *per-se* and the effects of volunteering: this included the main denominations in NI - with additional focus on more conservative Christian groups such as small Pentecostal or Evangelical churches (earlier analyses had

suggested higher levels of religiosity in this group^{5,6}); and also those stating no religious affiliation. Socioeconomic status was assessed using other census-based indicators including (i) household car availability (categorised into two or more cars, one only, no household access), (ii) educational attainment (third-level; intermediate; no formal qualifications) (iii) economic activity and, (iv) a combination of housing tenure and the capital value of the property. Capital value had been derived as part of an exercise by central government in 2005 to determine the level of local tax payable by each household, and linked to the working analysis database by the NISRA data management team when required. These data were combined with tenure from the census to produce an eight-fold classification of tenure/capital value of property: private renting; social renting; and, for owner-occupiers, five categories ranging from less than £75k to over £200k, with a separate category for owners with homes as yet unvalued.

In the 2001 Census the prevalence and extent of caregiving was based on responses to the question *'Do you look after, or give any help or support to family members, friends or neighbours or other because of, long term physical or mental ill-health or disability, problems related to old age?* Respondents had to choose from four options: No (non-caregiver); Yes, 1-19 hours per week; Yes, 20-49 hours; Yes, 50+ hours. Two questions on self-reported health were included in the 2001 Census: on the presence of limiting long term illness (LLTI), with a yes/no response; and on general health in the preceding year (GH) -with three responses – *good, fairly good* and *not good*. The fairly good and not good categories were both positively associated with increasing age and were sometimes combined into a single category for these analyses.

The 2001-based NIMS was used to study the relationship between caregiving and mortality risk and to our knowledge was the first in the world to do this over a complete population. We had been aware of one study in the US⁷ which had examined the mortality risk of caregiving: it showed that caregivers who experienced strain had a relative mortality risk of 1.63 compared to non-caregivers living with a non-disabled spouse; while those providing care but not experiencing strain had a relative mortality risk of 1.08. However, this relatively small study and had to be interpreted with caution.

Size matters

Our first study demonstrates two facets of census-based studies - (a) the benefits of large samples to study rare outcomes (in this case mortality), and (b) findings that say something generalizable about caregiving over a whole society. We showed that 14.3% of the non-institutionalised

population aged 16 and over were caregivers, with the majority (60%) providing 19 or fewer hours per week and 26% providing 50 or more hours⁸. Females and those currently married were disproportionately caregivers, though more so at higher caregiving levels. Socio-economic status was associated with caregiving: those providing 19 or fewer hours per week were more affluent and those providing more intensive levels (20 or more hours per week) were more disadvantaged than non-caregivers. These demographic and socio-economic characteristics are typical of caregivers in the UK and the USA⁹⁻¹¹. However, while the prevalence of caregiving in NI was a little higher than in other UK based studies, this was to be expected as the prevalence of caregiving is known to be related to morbidity levels¹³ and NI has some of the highest morbidity levels in the UK^{14,15}. Overall, caregivers had lower mortality than non-caregivers, though the risk amongst caregivers increased with time spent caring. Those providing 50 or more hours per week recorded lower mortality risks and adjustment for demographic, socio-economic and baseline health status at the census reduced but did not eliminate the mortality differentials between caregivers and non-caregivers: with Hazard Ratios (HR) 0.86 (95% CI 0.81, 0.93) and 0.75 (95% CI 0.69, 0.93) respectively in the fully adjusted models. This was the first study world-wide to demonstrate that although caregivers tended to have poorer levels of general health, they had lower mortality risk than their non-caregiving peers.

Generally epidemiologists are reassured when their results are corroborated in other populations - we were able to confirm the initial results using the Office for National Statistics Longitudinal Study for England and Wales (ONS-LS - the original model for NLS¹⁵). Although the cohort age-range was more constrained (35-74) than the Northern Ireland study, the magnitude of the differences between caregivers and their non-caregiving peers were very similar, for example relative risks of 0.87 (95%CI 0.79, 0.97) and 0.74 (0.66, 0.83) for men and women respectively engaged in more intensive caregiving duties.

Benefits of enriched census data

The third, fourth, and fifth papers benefit from the inclusion of an enriched set of self-reported health data in the 2011 Census – this allowed for (a) better adjustment for the baseline health status of caregivers than previously possible (important when examining subsequent mortality risk), and (b) it facilitated stratification by selected chronic conditions to test whether the mortality advantage associated with caregivers was a universal experience. For this the main addition was the inclusion of a question related to chronic conditions - *“Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?”* – which allowed people to tick any conditions from a list of ten that applied to them. For the 2011-based studies we selected four to see if

mortality by caregiving varied by presence of specific conditions: (i) *“a mobility or dexterity difficulty (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs lifting or carrying)”*; (ii) *“an emotional, psychological or mental health condition (such as depression or schizophrenia)”*; (iii) *“long-term pain or discomfort”*; and finally, (iv) *“shortness of breath or difficulty breathing (such as asthma)”*.

A new NIMS, constituted linking mortality records to the 2011 Census, was the basis for three further papers related specifically to caregiving. The first ¹⁶ showed that caregivers were less likely to report mobility problems than non-caregivers (odds ratio (OR) 0.94; 95%CI 0.92, 0.96), which may indicate health selection effects, given that a reasonable degree of dexterity is probably required to undertake a significant caregiving role. Notwithstanding this, the lower mortality risk for caregivers as a whole was similar to that derived from the 2001 data, and additionally, the improved data on baseline health status allowed stratification according to presence and type of chronic condition and analysis demonstrated that this mortality advantage was experienced by a wide array of caregivers and not just healthy caregivers (Figure 1). An examination of cause specific mortality showed that caregiving was associated with similar reductions in mortality risk across most major causes of death with possibly even lower risk from accidents and alcohol-related causes amongst men, suggesting that caregivers may engage in less risky behaviours.

Figure 1 about here

One significant recurring theme of caregiving research is the relationship to poor mental health outcomes. There is an established strong relationship between caregiving and stress¹⁷⁻²¹, with a high prevalence and incidence of depression²²⁻²⁷ or other common mental disorders^{28, 29}. Other studies suggest that caregivers are more than twice as likely to report thinking about suicide and wishing they were dead compared to non-caregivers³⁰. Collectively, these studies suggest that suicide risk should be higher amongst caregivers and that this should be related to the negative impact of caregiving on mental health. However, many of these findings were based on relatively small samples and the relationship to actual suicide was impossible to discern. Therefore, we undertook a separate study with a specific focus on mental health and suicide risk of caregivers

This showed that the likelihood of reporting chronic mental ill-health was higher in caregivers, with those providing 20 or more hours of caregiving per week about 30% more likely to report poor mental health, though about half of this was due to differences in socio-economic status. However,

and despite this higher prevalence of poor mental health, the fully adjusted models suggest that the overall risk of suicide for all carers was about 40% lower than that of non-carers (HR 0.59: 95%CI 0.41, 0.86), which was slightly lower than the risk of death due to non-suicide causes. The reduced mortality was evident even amongst those with more intensive caregiving duties. The relationship between caring and suicide risk was not modified by age ($P = 0.472$), marital status ($P = 0.901$) or the presence of chronic pain ($P = 0.921$), but was modified by baseline mental health status ($P = 0.060$); mental health at baseline did not modify the relationship between caregiving and non-suicidal causes of death ($P = 0.201$). The results of the stratified analyses presented in Figure 2 show that the caregiving is associated with a reduced risk of mortality from non-suicidal causes with little discernible difference in effect sizes between those with and those without poor mental health at baseline. A different pattern is evident for deaths due to suicide - while suicide risk amongst carers who did not report a chronic mental health problem is less than half that of their non-caring peers, carers with poor mental health were not significantly different from non-caring peers with poor mental health.

Figure 2 about here

Collectively, these studies plus other, generally US-based, studies using representative populations of caregivers and appropriate comparison groups³¹⁻³³ demonstrate that, despite the widespread perception of the generally deleterious effects on health, those engaged in informal caregiving are at lower mortality risk than their non-caregiving peers. However, as these are observational studies the possibility of uncontrolled confounding cannot be entirely discounted. Furthermore, one of the inherent limitations of census-based longitudinal studies is that they invariably start as cross-sectional and it is possible that those who took up a caregiving role were intrinsically more healthy (ie the healthy worker effect). There is some evidence for this both in the literature³⁴ and in these studies, indicating the lower prevalence of physical ill-health problems amongst caregivers. However, we do not believe that this is a major explanation as the effect persists even with the better ability to adjust for potential baseline health differences due to the enhanced health measures in the 2011 Census. The alternative explanation, that caregiving is associated with significant salutogenic effects is more likely, and the evidence supporting this has been increasing in recent years. Caregivers are generally more physically active which may help delay the natural age-related decline in physical and mental functioning. Additionally, a high proportion find their roles satisfying and rewarding, though perhaps one of the most important facets of caregiving is the increased sense of purpose it brings. Older adults who feel more useful have been shown to have

lower mortality rates³⁵ and that having a purpose in life buffers against mortality risk at most adult age groups and is independent of other markers of psychological or affective well-being³⁶. The reduced risk of suicide is perhaps a little surprising, given a higher prevalence of chronic poorer mental health and, from other studies, higher incidence of suicide ideation. However, it is known that the epidemiology of suicide ideation and suicide completion is different³⁷ and it may be that the salutogenic effects of caring outweigh the more negative aspects. Perhaps also the attendant sense of purpose may also protect against completed suicide due to a sense of responsibility on the part of the carer. However, although risk of completed suicide is lower, psychological burden may still be high.

Household-focused research

A recurrent theme in the literature is the additional distress and risk of poor health outcomes associated with informal caregivers who look after relatives or friends with dementia. This cannot be resolved directly using NIMS as the 2011 Census did not ask directly about the care recipient. However, in the final paper under review³⁸ we took the household structure information and made two assumptions: (i) that a person aged 65 or over who had reported in the Census that they had '*... frequent periods of confusion or memory loss*' which had or were expected to last at least 12 months represented a proxy for dementia (and the 19,845 cases selected for analysis was very close to estimates provided by the Alzheimer's Society); and (ii) that caregivers in the household were caring for the resident with dementia symptoms. The analysis showed that caregivers with more intensive responsibilities were no more likely than other household members to report chronic poor mental health (OR 0.97: 95%CI 0.81, 1.15), and that even in these households the lower mortality risk amongst caregivers was still evident (for example, hazard ratio (HR) 0.65: 0.53, 0.79). One important conclusion challenged the standard patient-caregiver dyad and advocated a *whole-family* approach: it may be that being in a household situation where a family member has dementia and not recognising oneself as a caregiver *is itself* the pertinent risk factor for stress, distress and poor mental health.

So far the focus has been on caregiving but, uniquely within the UK, the 2011 Census in Northern Ireland also included a question on volunteering: *In the past year have you helped with or carried out any voluntary work without pay?..* with a *yes/no* response. There were no supplementary questions related to duration or intensity of volunteering or the type of volunteering undertaken. This gave us the opportunity to examine the health effects of volunteering and the overlap between caregiving and volunteering.

Methodological advances

The aim of this study was to examine the relationship between volunteering and mortality risk³⁹. This had been the subject of some recent reviews⁴⁰⁻⁴⁶ and the associated lower risks were considered by many as established: indeed Okun *et al*⁴⁷ in a meta-analysis of 14 studies showed that organisational or formal volunteering reduced the mortality risk of people aged 55 and over by 24% (95%CI 16-31%) after adjustment for mediating factors, and concluded '*... it is no longer a question of whether volunteering is predictive of reduced mortality: rather... that the volunteering-mortality association is reliable and that the magnitude of the relationship is sizable*'.

However, this evidence base is derived from observational studies and the methodological shortcomings of meta-analyses based on observational data means there is still uncertainty as to whether the lower mortality risk associated with volunteering is a result of the activity of volunteering *per se* or a consequence of the special characteristics of those who choose to volunteer. This may be particularly important as those who volunteer are, by definition, self-selected and it is recognised that they differ markedly from those who do not volunteer across a range of factors related to mortality risk. It is well established that volunteers have higher levels of social and material resources^{48, 49}; tend to be more affluent, better educated, have better health especially physical health, better social integration and more religious involvement⁵⁰.

The ideal solution of randomisation is clearly impractical where mortality is the outcome, so our methodological advance was to build on the whole population coverage of NIMS to produce good estimates of mortality risk and to use the household relationship matrix (available for each household) to locate married partnerships, and compare outcomes within volunteer/non-volunteer married relationships to better adjust for measured and unmeasured household confounders than had been hitherto possible. This utilises the fact that partners largely share the same physical, social, and socio-economic environment and are often very similar across a range of other physical and behavioural attributes, thereby providing an additional implicit statistical adjustment for the social, environmental and lifestyle factors that may be associated with both volunteering and mortality risk, and which may have been inadequately captured or measured in previous cohort studies. We hypothesised that if the lower mortality risk associated with volunteering was due to unadjusted or poorly controlled confounders present at the household level then this lower mortality risk would also be seen amongst the non-volunteering partners of these volunteers. If on the other hand

volunteering has a real and direct effect on the volunteer then a mortality advantage should be evident for the volunteer, but not for their partner.

The first finding was that this ostensibly naïve Census question on volunteering produced estimates and socio-demographic distributions characteristic of other studies. Of the 617,466 individuals aged 25 and over at baseline, 16.3% identified as volunteers who tended to be more affluent, better educated, to be part of more conservative religious affiliations and to be physically and mentally healthier than non-volunteers. Follow-up, for thirty-three months, showed a mortality risk of 0.79 (95%CI 0.71, 0.85) for males and 0.77 (95%CI 0.68, 0.88) for females, both very close to the estimates from the meta-analysis mentioned above. However, the main finding was that amongst co-habiting married couples where one partner is a volunteer, the effects of volunteering are seen only in the volunteer and not in their non-volunteering partner - evidence that the lower mortality associated with volunteering is not due to unmeasured or poorly adjusted-for confounders.

Insert Figure 3 about here

In the final paper we examined the overlap between both pro-social activities. We thought this important for a number of reasons: (a) because of the potential ambiguity in the definitions and potential for misclassification; (b) because some findings from other countries showed a reasonably significant overlap between these activities^{52,53}; and (c) because of increasing interest in those engaged in both volunteering and caregiving activities (so-called *super-helpers*)⁵⁴. An analysis of the 2011 Census data, focussing on a cohort aged 65 and over with mortality follow-up for 45 months, showed that although there was a significant overlap of caregivers and volunteers, there were also significant differences between them. The overall prevalence and overlap in activities is shown in Figure 3 - with just over 20% of caregivers also involved in volunteering, and 23% of volunteers involved in caregiving. Fully adjusted logistic regression models showed that although both volunteers and caregivers were less likely to report chronic mobility problems than those not engaged in either activity (OR 0.93: 95%CI 0.89, 0.96 and OR 0.90: 0.85, 0.94 respectively), caregivers were more likely and volunteers less likely to report chronic poor mental health (OR 1.07: 1.00, 1.14) and OR 0.87: 0.79, 0.96 respectively). However, for those engaged in both activities, levels of mobility were closer to those of people volunteering only, with mental health outcomes closer to those engaged in caregiving only. The mortality risks for volunteering and caregiving were identical

(HR 0.75: 0.72, 0.78 and HR 0.75: 0.71, 0.79) and, although there was no significant interaction between them suggesting separate effects on mortality, the lowest mortality risk was seen in those engaged in the combination of volunteering and light caregiving (less than 20 hours per week) - HR 0.53: 0.45, 0.63. This study provides some evidence of a synergism of action, at least at lower levels of caregiving, with perhaps benefits accruing from both the bonding effects associated with caregiving and the outward-looking social engagement associated with volunteering. This was not evident at higher levels of caregiving, perhaps because the stress of too many significant roles can off-set any additional accrued benefits.

Conclusions and summary

There are two general sets of conclusions from this work: the first relates to the untapped utility of administrative data sources for research and policy gain; the second to the substantive findings on prosocial activity, and particularly caregiving. We show that administrative data can, in some research scenarios, offer significant advantages over other methodological approaches in terms of efficiency and cost. The wider population coverage minimises selection bias and the nature of the data as routinely collected obviates responder burden and recall bias - problems which can beset other survey methods. The potential dynamic of linkage to other administrative data only enhances this utility. This is why both the UK and Ireland are advancing initiatives to increase access to linked administrative data^{55, 56}. However, it is important to acknowledge the limitations and potential caveats associated with these data. As this paper demonstrates, Northern Ireland was fortunate that (a) the 2011 Census included questions on *caregivers*, *volunteers* and extensive measures of self-reported *chronic ill-health*, and (b) that we have an institutional infrastructure in place to facilitate the safe analyses of de-identified linked individual-level data. However, space in the Census is limited and, as we have seen, such data is rarely exactly what researchers desire, certainly in comparison to what would be available in dedicated surveys. There may also be uncertainty about the provenance and face-validity of some census variables such as the chronic health conditions, which can potentially undermine research. Given the costs associated with including any questions it seems strange in retrospect that such un-validated questions are included at all. One further issue - related to coverage - has surfaced in administrative databases: even the census falls short of total population coverage and under-enumeration at the 2011 NI census was estimated at 8% overall, with proportions amongst younger adults, males, migrant groups and those in inner city and deprived areas even higher. The implication of this is that the ability of routine administrative datasets to make unbiased statements about crucial policy relevant groups such as the more socially excluded may be compromised. Finally, it is recognised that sometimes even the Northern Ireland population is not extensive enough to provide robust answers, which is why we occasionally go to

other countries either within the UK or further afield (for example, building links with research institutes in Scandinavian countries with well-established record linkage potential based on their population registration systems).

Notwithstanding these limitations, the linkage of mortality records to the 2011 Census enabled new light to shine on the health effects of volunteering and caregiving. Collectively the studies reported here support the tone of two recent reviews^{57, 58} that have argued eloquently for a more balanced perspective on caregiving, suggesting that '*policy reports, media portrayals, and many research reports commonly present an overly dire picture of the health risks associated with caregiving and largely ignore alternative positive findings*'. That this research can be cast as a corrective to any such overly dire perspectives at a time of increasing need against a background of an ageing population and a decline in formal support services and traditional family caregivers is a positive note on which to end this review.

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Figure 1: Risk of death according to hours spent caregiving per week, for those with selected chronic health conditions. Data represents Hazard Ratios (and 95% CIs) from Cox Proportional Hazards models fully adjusted for age, sex, ethnicity, marital status, housing tenure car availability and area of residence.

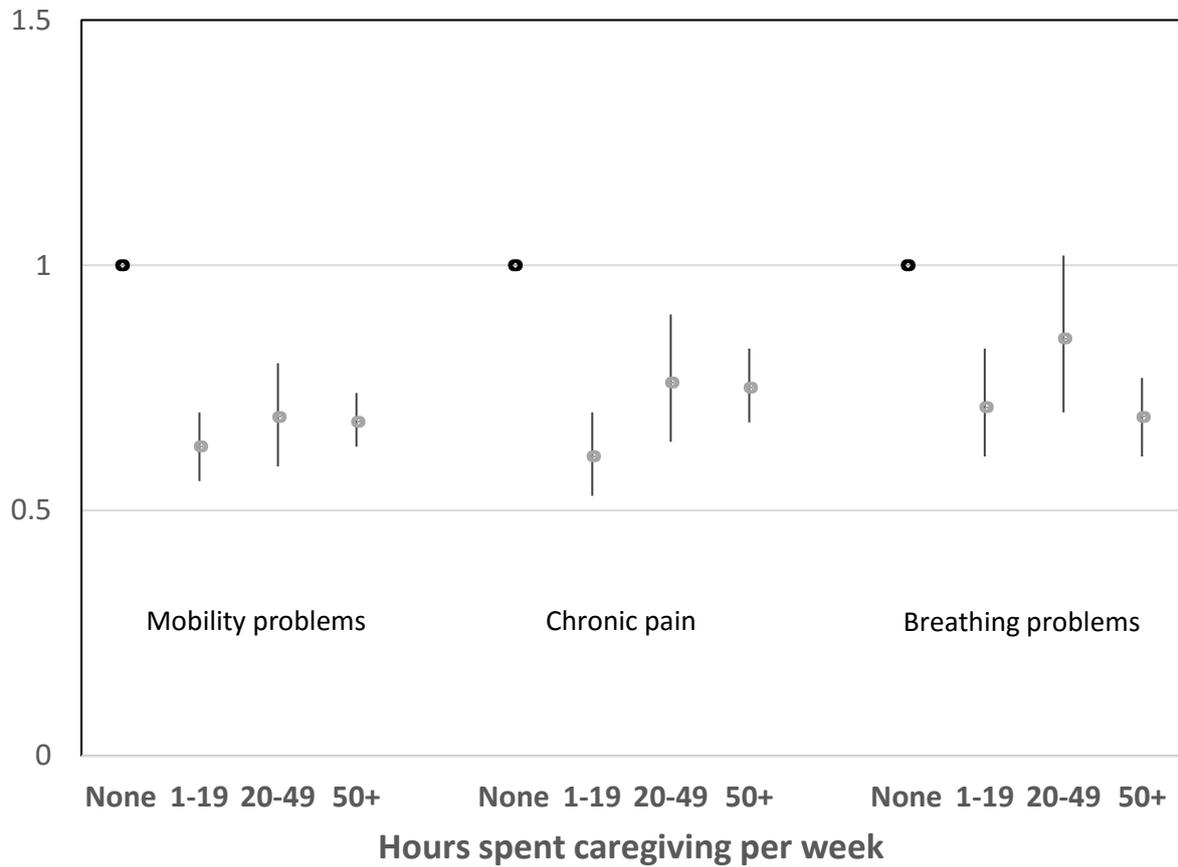


Figure 2: Risk of death due to suicide (squares) and to non-suicide causes (circles) stratified by presence of a chronic mental health condition (non-solid marker). Data represents Hazard Ratios (and 95% CIs) from fully adjusted Cox Proportional Hazards models.

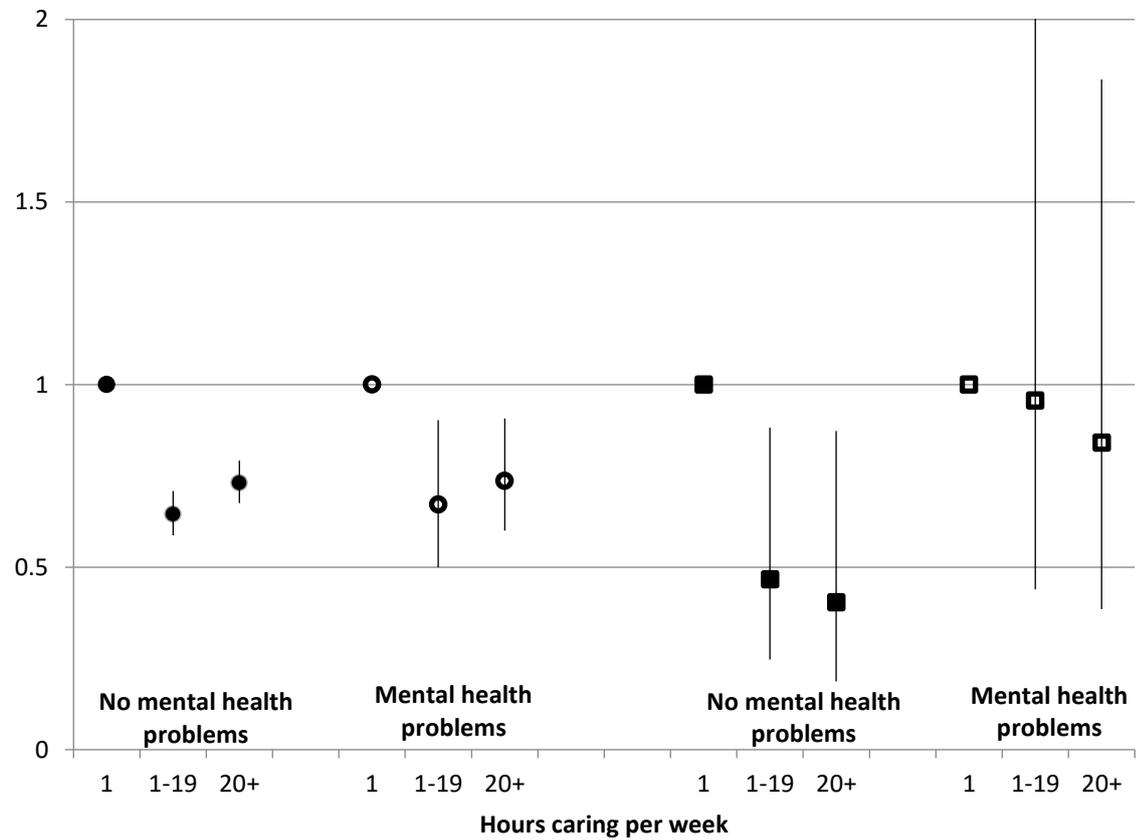


Figure 3: Prevalence of volunteering and caregiving amongst 244,429 people aged 65 and over, at the time of the 2011 Census

