

## Using Administrative Data to Change Perception about Caregiving and Improve the Evidence Base Related to Volunteering

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**Abstract:** 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.

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**Keywords:** caregiving, volunteering, United Kingdom

**JELs:** J10, J14

### 1. INTRODUCTION

The primary function of this paper is to demonstrate how the availability and analysis of large administrative datasets can be used to undertake the definitive studies needed to dispel persistent and commonly held beliefs that have arisen about caregivers and volunteers. In passing we will also show how these 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 will provide some counterbalance and review the limitations of the current data, and conclude by making suggestions for improvement in future censuses.

### 2. POLICY RELEVANCE

The studies are thematically linked and focus on prosocial activity - people involved in *volunteering* and *informal caring* (or *caregiving* as it is now 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 definition [1], 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 volunteering [2] and an element of overlapping misclassification with caregiving [3] 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.

The difficulties experienced by caregivers was highlighted in a recent report from AgeUK [4] and further elaborated in a subsequent Lancet editorial entitled '*Who cares for the carer?*' [5]. These articles summarise the huge contribution made by caregivers and emphasise that many are doubly vulnerable as they are both likely to

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be elderly and in poor health. They conclude that the pressures on caregivers are likely to increase in forthcoming years as the population ages and formal caregiving services come under greater financial pressures. However, the perceived picture of caregiving is one associated with significant levels of stress and burden which have deleterious effects on the caregiver's wellbeing [6-10] and the apotheosis of this narrative was a paper in 1999 from Schulz and Beach showing that caregiving was a significant risk factor for mortality [11]. This paper struck a chord with the caregiving stakeholder community and with the related research community where it has been cited over 3,000 times in other academic papers. But is this picture correct? The Schulz and Beach study was small and based on a selected group of caregivers, with a debateable control or reference group. To provide a more definitive description of the relationship between caregiving and mortality we must turn to linked administrative data, but first we will describe our data sources and associated methods.

### 3. 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 administrative data will be described in the course of the paper.

### 4. 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 elsewhere [12]. 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 [12-13]; 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. This was to extend the Schulz and Beach study in the US [11] which had examined the mortality risk of caregiving for just under 400 caregivers: 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.

### **5. IS CAREGIVING ASSOCIATED WITH AN INCREASED RISK OF MORTALITY?**

The answer, based on an analysis of individual-level linked administrative, is in general ... 'no', but our first study also demonstrates two valuable 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 hours [15]. 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 USA [16-18]. The prevalence of caregiving in NI was a little higher than in other UK based studies, but this was to be expected as the prevalence of caregiving is known to be related to morbidity levels [19] and NI has some of the highest morbidity levels in the UK [20-21]. Overall, caregivers had lower mortality than non-caregivers, though the risk amongst caregivers increased with time spent caring. Those providing very intensive levels of caregiving i.e. 50 or more hours per week also 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) for males and females 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 - and 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 NILS) [22]. 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.

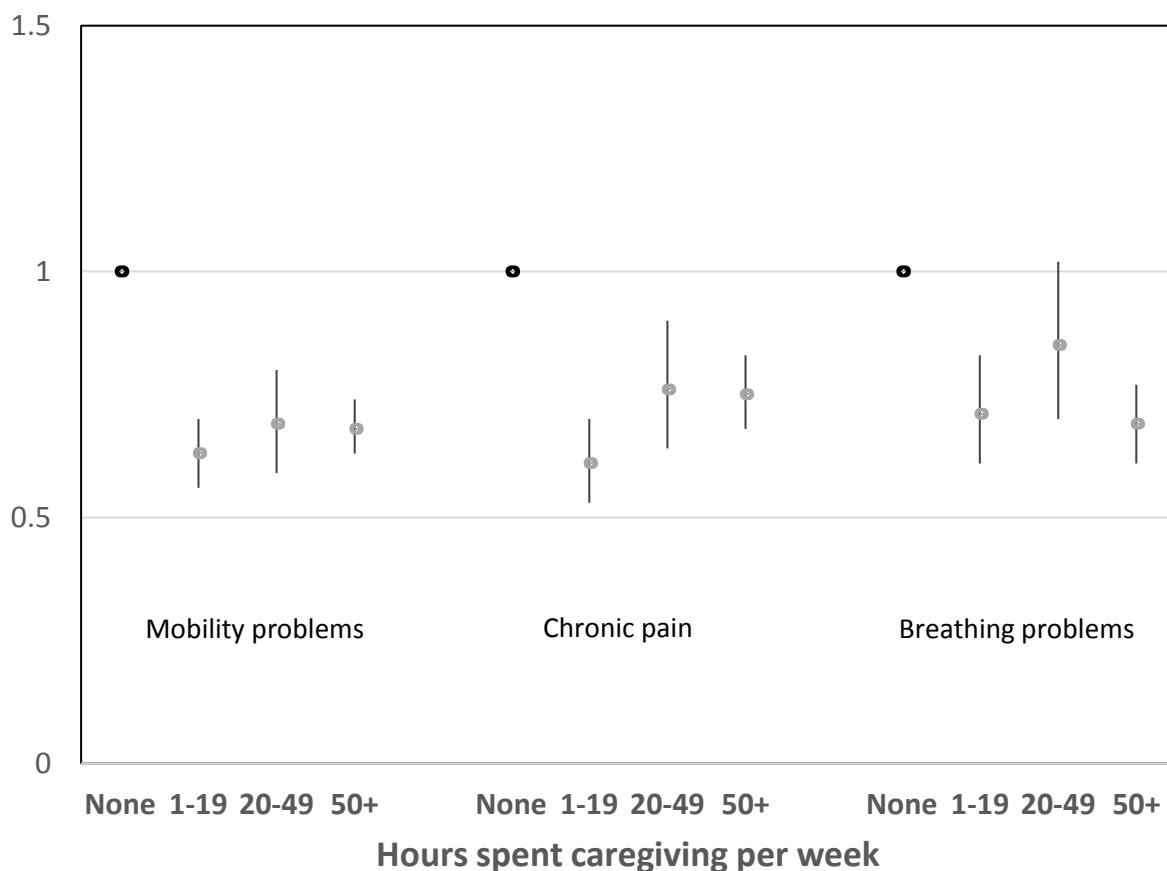
Interestingly, neither the NIMS nor ONS-LS studies, which demonstrated a lower mortality risk, received anything like the interest that the original Schulz and Beach study did, and this one positive association between caregiving and mortality continues to be widely reported in the academic and caregiver stakeholder community. Indeed despite our early epidemiological evidence to the contrary, studies focusing on the biological effects of caregivers were continually pointing in the opposite direction. Such studies were demonstrating that caregivers had abnormal biomarkers, an excessive inflammatory burden, changes suggestive of premature ageing of the immune system, and shortening of the relative telomere length (a marker for cellular ageing) [23-24]. It was usual for the abstracts of these studies to conclude that '*These changes .... may place them [caregivers] at risk for morbidity and mortality*'. For many this looked like incontrovertible proof, rendering the actual study of mortality effects redundant. So, when the new 2011 Census data became available we drew on its enhanced health data to once again study the relationship between caregiving and mortality but this time in more depth and more detail.

### **6. BENEFITS OF ENRICHED CENSUS DATA**

The third, fourth, and fifth papers in our series benefited 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 only amongst the most healthy or a more universal and generalizable experience. The main addition was the inclusion in the 2011 Census of a question related to the presence of chronic conditions - "*Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?*" – with instructions for people to tick any conditions from a list of ten that applied to them. For the 2011-based studies we selected the following 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 [25] showed that caregivers were less likely to report mobility problems than non-caregivers (odds ratio (OR) 0.94; 95% CIs 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: 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.**



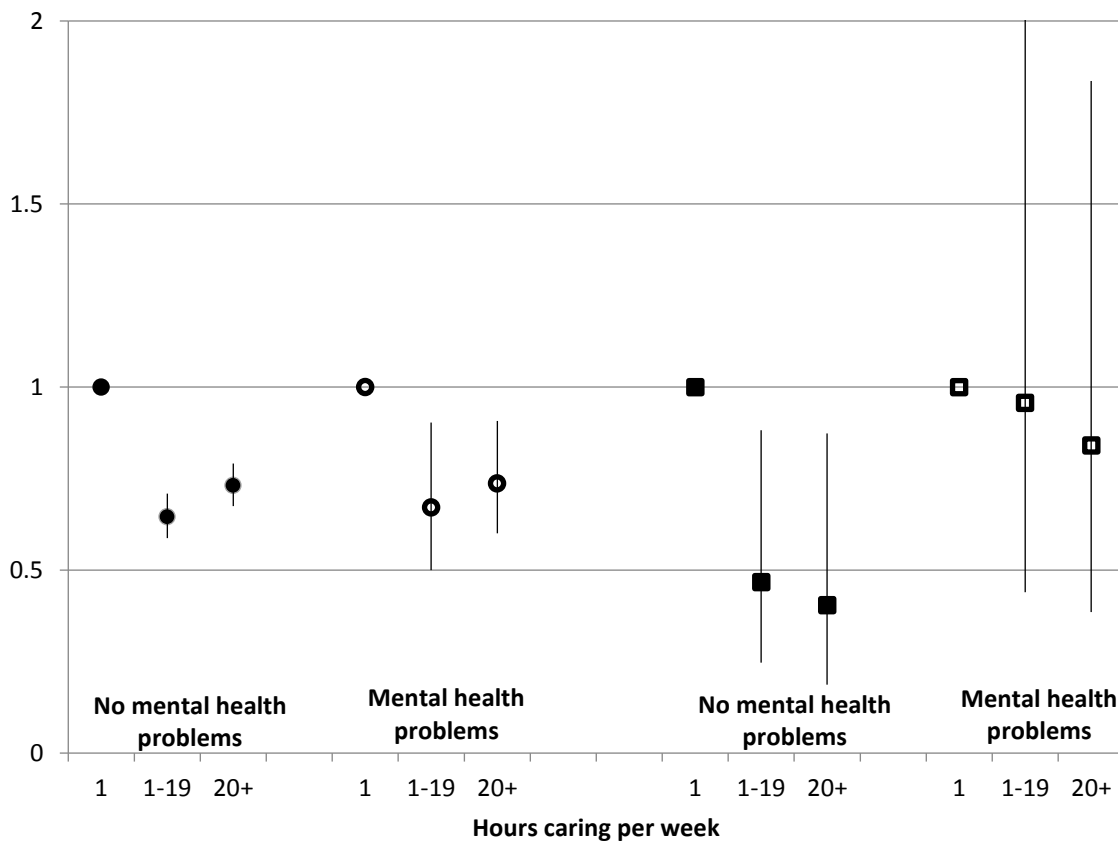
### 7. IS CAREGIVING ASSOCIATED WITH AN INCREASED RISK OF SUICIDE?

One significant recurring theme of caregiving research is the relationship to poor mental health outcomes. There is an established strong correlation between caregiving and stress [7-10], with a high prevalence and incidence of depression [26-31] or with common mental disorders [32-33]. Other studies suggest that caregivers are more than twice as likely to report thinking about suicide and wishing they were dead compared to non-caregivers [34]. 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 numbers of caregivers and compounded by the inability to undertake a follow up study, the relationship to actual suicide was methodologically impossible to discern. Therefore, we undertook a separate census-based study with a specific focus on mental health and suicide risk of caregivers.

This confirmed that the prevalence of 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: 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.**



### 8. BUT CAREGIVING FOR SOMEONE WITH DEMENTIA IS DIFFERENT?

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 review [35] 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.

Collectively, these studies plus other, generally US-based, studies using representative populations of caregivers and appropriate comparison groups [36-38] 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 literature [39] and in the current 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 rates [40] 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-being [41]. 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 different [42] and it may be that the salutogenic effects of caregiving 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.

So far the focus we have been using these linked administrative data to debunk some of the widely held beliefs about the deleterious effects of caregiving. Now we demonstrate how they can be used to bolster the evidence base related to the relationship between volunteering and mortality risk where the evidence base has been weak. Again we build on the 2011 Census in Northern Ireland, which uniquely within the UK, 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.

## 9. WHAT ABOUT VOLUNTEERING?

The aim of this study was to examine the relationship between volunteering and mortality risk [43]. This had been the subject of some recent reviews [44-50] and the associated lower risks were considered by many as established: indeed Okun *et al* [51] 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% CIs 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 [52-53]; tend to be more affluent, better educated, have better health especially physical health, better social integration and more religious involvement [54].

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.

## 10. CONCLUSIONS AND SUMMARY

There are three 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 recently with the increased use of administrative databases: even the census falls short of total population coverage and overall under-enumeration at the 2011 NI census was estimated at 8%, 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).

Finally, it is clear that many studies of caregivers based on surveys and most of those examining the correlates of caregiving at the biological or cellular level would quite logically conclude that it is associated with an increased risk of early death and or risk of suicide. However, it is clear that this conclusion is very wide of the mark and that caregiving is actually associated with a marked reduction in mortality risk. This demonstrates that logic alone is insufficient to bridge a shortfall in the evidence gap. There is no shortcut to studying actual mortality effects and the presence of large population wide linked studies now make this, and other such studies feasible and practical. 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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### **FIRST VOTE OF THANKS PROPOSED BY BRENDAN WHELAN**

Throughout my professional life I have been involved in the design and analysis of surveys, many such as TILDA focussing on care giving and social support. As a consequence, I found this set of studies fascinating from both methodological and substantive points of view. The paper shows how linked administrative data can obviate many of the serious difficulties faced by surveys, both of the general population and of specific sub-populations. This type of data is cost effective and substantially reduces the problem of non-random participation bias which has dogged survey research in recent years. It also allows for the study of rare or scattered sub-groups which would be prohibitively expensive to identify and interview using conventional survey approaches.

Substantively, the papers focus on topics of growing importance, namely the prevalence of the pro-social activities of care giving and volunteering. Policies to promote and enhance these activities are of increasing relevance in an ageing society where family size is falling and formal support services are coming under severe financial pressure.

I was struck by the authors' clever linkage of a number of databases, including the Censuses of Population of 2001 and 2011, the Northern Ireland Mortality Study and the 2005 exercise in estimating property capital values. Their approach shows the value of having access to a range of databases and being able to use them for purposes for which they were not originally designed.

The authors' strong and consistent finding that caregivers experience lower mortality is striking and would, I think, come as a surprise to most. I would be interested if the authors would care to speculate as to why the Schulz and Beach study which they quote on page 3 produced such different results.

The results in relation to suicide are even more striking. Although caregivers reported higher levels of mental ill health (and therefore likely to have higher levels of suicidal ideation), the prevalence of actual suicide for all carers was about 40 per cent lower than that recorded for non-carers. This shows the danger of inferring that consistent thoughts about suicide are necessarily likely to lead to the action.

The authors utilise the household-based nature of the databases in two ingenious ways. First, they look at the distress and poor health outcomes associated with caring for dementia sufferers. They identify the caring dyad within the household and this allows them to deduce that even this highly stressed group of carers recorded a lower risk of mortality than non-caregivers.

Turning to volunteering, the authors confirm the result from numerous international studies that volunteering is predictive of lower mortality. They go on to show that this result is not due to unmeasured confounders. They do this by comparing volunteers with their non-volunteering partners and show that volunteering has a real and direct effect on the volunteer's mortality.

Finally, some questions on how to improve the use of administrative databases in the future. Would the authors like to speculate on the extent to which data protection restrictions have proved a barrier to such use? In my experience this is a major problem for academic and non-governmental agencies. Secondly, would it be desirable to do more validity testing of the questions to be included in the Census?

### **SECOND VOTE OF THANKS PROPOSED BY ROSALYN MORAN**

#### ***Introduction***

I would like to thank Norman Caven, Honorary Secretary for inviting me to second the vote of thanks to Professor Dermot O' Reilly and to provide some comments on this innovative work which illustrates the value of using administrative data to elucidate the health and related implications of two forms of pro-social behaviour, namely caregiving and volunteering. Both of these activities are increasingly important in society as our population age, our formal social and health services experience increasing strain and new technologies create challenges, as well as opportunities for social contact.

Results of research indicating the negative health implications of caregiving have seeped into popular culture, however, the studies presented here provide strong findings which show that those providing care also benefit from lower mortality risk. Using data from the Northern Ireland Mortality Study, NIMS and more detailed health data from the 2011 census data, the investigators were able to tease out several important findings relating to the health and wellbeing of caregivers. They were able to look at interfamilial factors, risk profiles in relation to infrequent events such as suicide and alcohol related deaths. Generally the findings point to a less deleterious effect of caregiving on the carer than heretofore believed and to the positive mental and physical health associated with volunteering.

The studies reported on, in some cases supported findings in the literature which were based on less strong evidence. Other studies provided new insights, some contrary to received wisdom. Several of the findings have important policy implications.

### ***'Making a difference' through the use and linkage of secondary data***

The studies reported by Dermot in this paper concentrating as they do on linking the whole enumerated population of Northern Ireland (1.7 million people) from the census to subsequent registered deaths recorded in the General Register Office (The Northern Ireland Mortality Study, NIMS) are but the tip of the iceberg – Dermot and his colleagues have carried out a major body of work linking NIMS and census data to data from the Northern Ireland Longitudinal Study, NILS<sup>2</sup> (NISRA 2016a). This range of data is a researcher's dream but there is more – these data sources can be linked to a variety of data in the health area e.g. hospital and laboratory data, prescribing data, cancer registry data, dentistry records etc. since each person's *Health and Care Number* is part of the NILS dataset. Studies involving this kind of sensitive data are not routinely linked however – such 'distinct linkage projects' each require specific ethical approval, inter alia, in addition to the rigorous safeguarding processes and procedures which are required for studies involving routinely linked data.

This work has allowed for

- Exploitation of *existing* data. (Data is one of our greatest national assets which is costly to gather and maintain. Thus it should be used to the full for economic and social benefit).
- The large numbers involved have allowed for study of *rare events* (e.g. suicides) and sub-groups of the population
- The datasets allow for study of *changes over time*, life-course transitions and teasing out cause from effect – natural experiments etc.
- Area based studies and exploration of *spatial aspects* of health and related phenomena.

These data sets have allowed a wide range of important issues to be explored - research has been conducted on health inequalities, migration, segregation, the labour market inequalities, uptake of breast screening, antibiotic prescription, medication use pre and post admission to nursing homes, fertility, socio-economic differences in use of dental services, mental health within families, homelessness etc. These studies have helped to inform and monitor policy and practice in education, health, justice and spatial planning. In addition, the work carried out has made significant contributions to the academic literature and has provided career development opportunities for academics and undergraduate students.

### ***Development of enabling infrastructure and services in NI***

This potential for carrying out such important and relatively inexpensive significant research was not conferred on the scientific community and administrative data scientists of Northern Ireland overnight - it is important to point out some of the factors which have enabled this kind of work.

The Northern Ireland Longitudinal Study and NIMS provided the basis for a productive and fortuitous collaboration between the **research community**, a government statistical agency and an Office of the Register General, ORG - the NISRA/NILS/NIMS collaboration. As always it was visionary people who set and stoked this fire and I will mention some but of course I cannot mention all names here – Professor Dermot O'Reilly from Public Health in QUB, David Marshall from NISRA and Norman Caven from the ORG and their respective teams. These championed the opportunities provided by safe use of data to inform policy and practice and established fruitful collaborations with fellow travellers in the UK and internationally. NI has been party to a number of cross UK initiatives (e.g. ONS-Longitudinal Study, Scottish Longitudinal Study, and the Administrative Data Research Network).

Importantly, funding has been forthcoming to support infrastructural developments and to support the research which has used the data to inform policy and planning as well as contribute to the academic literature. The NI infrastructure is now funded by Health and Social Care, Research and Development Division of the Public Health

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<sup>2</sup> NILS is a sister project to similar initiatives in England and Wales [ONS-LS] and Scotland [SLS]. NILS was started, as was NIMS, in 2006. NILS which covers 28% of the NI population (circa 500,000 people) is based on [regularly updated] demographic data from the Northern Ireland Health Care Registration System and subsequent censuses and linked to a variety of data sources including administrative and other data sources.

Agency while the very important support function (NILS-Research Support Unit) is funded by the Economic and Social Research Council and the Office of the First Minister and Deputy First Minister for Northern Ireland.

Since the initial funding of NILS and NIMS in 2003 a highly sophisticated architecture which ensures the safe use of data has been put in place. Early on a safe haven environment was established and as an appreciation of the value of research involving data linkage (including use of personal data) grew, a sophisticated array of infrastructure and services (for example, the honest broker service, data linkage service) bolstered by an array of safeguarding processes and practices underpin by sound governance (e.g. an authorising entity, approvals mechanisms, training, licensing, codes of practice etc.) developed over a number of years. These developments and related protocols are exceedingly well documented. Ab initio good governance and safe data practices were to the forefront of developments along with a concern for public engagement. The resulting NISRA infrastructure and services is in accordance with emerging international best practice (see Moran 2016).

The infrastructure developed has enabled a formidable body of research. As of May 2016 there have been 105 approved projects (71 NILS and 34 NIMS) involving 155 distinct researchers (NISRA 2016b). All this at a modest cost from 2003 to 2016 i.e. a thirteen year period, of £4.6 million<sup>3</sup> with a business as usual annual cost of £380,000 (NISRA 2016). You have to agree, given the range of studies outlined above, that this is indeed value for money! The presence of this infrastructure was important to the establishment of the Administrative Data Research Network, ADRN node in NI in 2013, one of four such nodes in the UK. ADRNs are tasked with helping social and economic researchers gain access to administrative data in a safe and lawful way to inform policy<sup>4</sup>. The NI ADRN is a collaboration involving NISRA, QUB and the University of Ulster and has produced several research studies of value in the policy context.

### ***Republic of Ireland – Yet to Catch Up***

Regrettably the scientific infrastructure which enables this type of important work has not been developed in the Republic of Ireland, ROI.

We, in the Health Research Board frequently hear from researchers whom we fund, that they experience difficulties in accessing certain data sets and in trying to carry out important work which can inform health policy and practice because they cannot safely link data (see Moran 2016). In some cases studies have to be abandoned or suffer inordinate delays resulting in loss of evidence based inputs to policy and practice as well as considerable frustration to researchers. Consequently the HRB initiated work to explore the issues involved and to examine what needed to be done.

The outcome of this work which involved extensive consultation with stakeholders nationally and internationally was the DASSL model (Moran 2016). DASSL identified the infrastructure and services required in Ireland for the safe Access, Storage, Sharing and Linking of Data – hence the DASSL acronym but also analysed the socio-cultural, legal, technical environment in which the model would operate. The model was informed by international best practice including the work carried out in NISRA.

The original focus of the HRB work was on the use (access and linkage) of data in the health area but it soon became apparent through interviews with a range of stakeholders in a variety of domains that the access and linkage difficulties and opportunities foregone were experienced by data users across the data landscape in Ireland.

### ***The DASSL Model***

The seven main elements of the DASSL model are outlined in figure 1 below – *Governance, A Research Data Hub, A Trusted Third Party Indexing Service and A Data Linkage Service, A Safe Setting/Haven, A Research Support Unit, Output Checking and Disclosure Control and Public Engagement*. This is the infrastructure and the services needed in the ROI to enable us to carry out work like that presented by Dermot today.

It is proposed in the HRB report that a **Research Data Trust** is set up to house the infrastructure and services needed to enable researchers and data users in the ROI to access and use linked data in accordance with international best practice in the safe use of data.

In addition, it is recommended that an **authorising entity** is established based on the Principled Proportionate Risk Based Approach to data governance (see Moran 2016). Such an entity should be suitably appointed and have

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<sup>3</sup> This includes the 2011 and 1991 census linkage exercises.

<sup>4</sup> <https://adrn.ac.uk/about/background/history/> ; The ADRN gives trained researchers access to linked, de-identified administrative data in a secure environment.

people with appropriate expertise who can balance personal privacy with public good in accordance with guiding principles etc. and in so doing adjudicate on projects, which involve access and linkage of data – making go /no go decisions.

Implementation of the DASSL model will serve the extant and emerging needs of researchers and data analysts across the economic and social spectrum and allow them to optimise the use of our national data assets for economic and social gain.

A report outlining the DASSL model was launched in Dublin in May 2016. There was general agreement at the launch of the report, which was attended by the major stakeholders, that the type of infrastructure and services outlined in the DASSL model were urgently needed in Ireland. This accord was reflected in subsequent presentations of the model e.g. to the National Statistics Board, Health Research Board, Health Information Society of Ireland communities, inter alia.

A number of elements of the DASSL model exist within the CSO (e.g. protected data linkage using research micro files, safe haven environment, disclosure control etc.) but they are of very limited use to researchers who work on data which do not fall within the definition of ‘official statistics’<sup>5</sup> as defined in the Statistics Act 1993. Accordingly, the very welcome developments in the CSO in recent times to advance the Irish Statistical System e.g. Administrative Data Centre, Statistical System Coordination Unit, Researcher Coordination Unit will benefit those working on official statistics but the CSO mandate will not benefit researchers working on data sets which fall outside the definition of ‘official statistics’. The DASSL model is needed to enable safe use of such data for economic and social gain and to respond to demands posed by developments in data science, open data, open science and to avail of opportunities provided by new and emerging developments in supercomputing, big data, data analytics etc. The transposition of the General Data Protection Regulation provides a unique opportunity to provide a legal basis for the DASSL safeguarding infrastructure and services.

#### *Going Forward*

The infrastructural developments which enable the kind of work presented by Dermot would not have been possible without strong leadership, political will and as seen above, modest funding. NI along with several other countries<sup>6</sup> has developed DASSL type infrastructures as an essential part of their scientific and research infrastructure. We have learnt a great deal from personnel in NISRA/NILS and of course Dermot as well as international colleagues where similar initiatives exist while developing the DASSL model. I would like to thank them sincerely for their generosity with their time and expertise. As you have proved here in NI, the infrastructure for sharing and linking data can help realise part of the vision outlined in *Innovation 2020* (ICSTI 2015), Ireland’s strategy for research and development i.e. to create ‘an internationally competitive research system that acts as a magnet and catalyst for talent and industry’.

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<sup>5</sup> Official statistics – under the Statistics Act 1993, ‘Official Statistics’ are agreed between the Director General of the Central Statistics Office (CSO) and the head of a public authority which compiles statistics when the statistics ‘are considered to be of sufficient public interest and satisfy the following criteria:

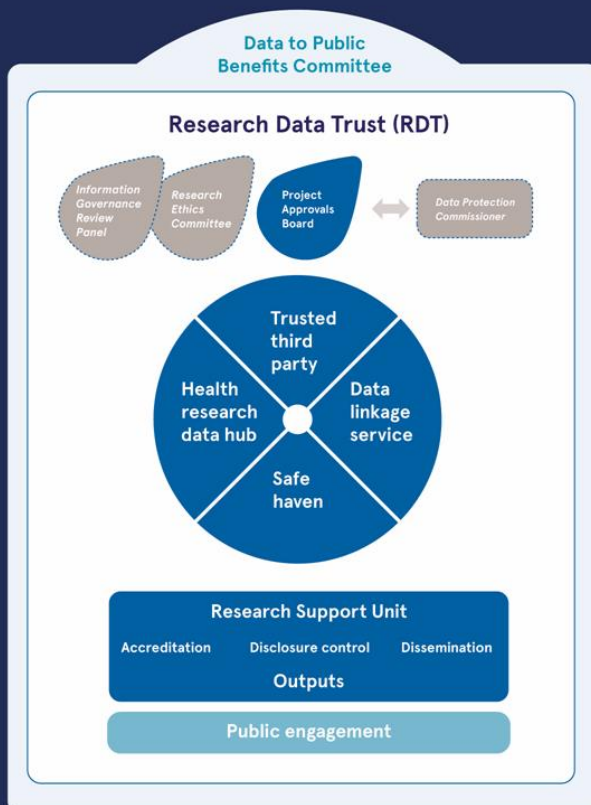
- produced by or on behalf of a public authority
- continuous i.e. there should be a reasonable expectation that the published statistic will be updated with new data to provide comparability over time
- where a statistic is produced as a “one-off” the Director General of the CSO, in consultation with the responsible public authority, may deem the statistic an Official Statistic if it is considered to be of public interest
- in the public domain.

The list of Official Statistics will be developed and updated over time’ <http://www.isscop.ie/officialstatistics/>

<sup>6</sup> (e.g. England, Scotland, Wales, Canada, Australia, New Zealand etc. see Moran 2016).

## Figure 1: The DASSL Model

The DASSL model is composed of seven main elements which need to be put in place to ensure data privacy and security for Irish data users and citizens.



The seven elements of the DASSL model are

- **Governance** – sound governance is a prerequisite for all research but particularly where a balance has to be struck between privacy and individual interests and public benefit. Good governance requires compliance with legislation and proportionality in achieving this balance. An approach should be guided by key principles and by robust and transparent policies, processes and procedures for holistic risk assessment. These should be informed by stakeholder engagement.
- **A Health Research Data Hub** – to provide and facilitate safe access to protected data in accordance with agreed governance arrangements
- **A Trusted Third Party Indexing Service and A Data Linkage Service** – to allow for safe data access and secure anonymised data linkage. A number of advanced techniques have been developed to protect data and to safeguard against re-identification of individuals
- **A Safe Setting/Haven** – a ‘locked down’ , highly secure environment designed to allow researchers and other accredited data users to process sensitive data safely
- **A Research Support Unit** – to provide oversight, management and support functions to data users and custodians thus ensuring safe and efficient use of data – 15 functions are outlined in the report. The Unit would accredit, train and support researchers ensuring that ‘safe protocols’ were adhered to in the usage of the data, infrastructure and services provided.
- **Output Checking and Disclosure Control** – employment of best practice to ensure that data outputs are safe and free of any possible identifiers prior to the release of data.
- **Public Engagement** – the model recommends a programme of public engagement to ensure transparency and to maintain the trust and support of the general public. People who provide their personal information for research need to be confident that their data will be used in the public interest; that the data is held securely, and that their privacy and confidentiality will be respected.

## DISCUSSION

**Norman Caven:** I note that the paper showed the value of being able to link administrative and Census data in a safe setting and raised a number of important policy insights and considerations. The authors make reference to the value of the reproducibility of findings as had been found between their work and the GB Longitudinal Study. I ask whether Scottish data, where the 2011 Census had also included questions on caring and health conditions, had been analysed in a similar way.

**Richard Elliott:** I notice in your analysis that the risk of mortality seems to increase for carers as they get younger. This is very interesting and it strikes me that this might be because, as younger people, the caring may well have been forced upon them at a time when they have a number of other responsibilities – such as either being a full-time student or in full time employment. As such, you could argue that the impact that this is having on the carers is that they have increased stress as a result, thus potentially contributing to a higher risk of mortality. I wonder have you considered widening your analysis to including variables such as “student status” or “occupation” (both available from the Census) in your analysis to ascertain if this is indeed the case.

**Deborah Hyden:** Although the importance of shared identity in giving (Levine, Prosser, Evans, & Reicher, 2005) and receiving help (Haslam, Jetten, O'Brien, & Jacobs, 2004) is now well established. Few studies have considered the importance of identity dynamics in the context of informal caring. Among formal carers, however (Patton, Ware, McPherson, Emerson, & Lennox, 2016) have acknowledged the role of the social identity approach to explain how perceived lack of social support could contribute to carer stress. In particular, they concluded that not only could the social isolation experienced by carers contribute to negative well-being, but that carers could also begin to define themselves predominantly in terms of an undervalued social group. In addition, (Bjerregaard, Haslam, Morton, & Ryan, 2015) noted the importance of identity congruence between care-worker and client for the carer's wellbeing in formal care settings. However, given that informal care is often provided out of a sense of duty (Harding & Higginson, 2001), it is important to consider the implications that may follow for the caregiver should they fail to identify with the person in need, which is likely to occur when younger individuals are providing care for older adults.

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