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Caregiving, volunteering or both? Comparing effects health and mortality using census-based records from almost 250,000 people aged 65 and over.

Running Head: Health effects of caregiving and volunteering

Authors:

Dermot O'Reilly MD¹; Michael Rosato PhD²; Finola Ferry PhD²; John Moriarty PhD³; Gerard Leavey PhD²

Affiliations:

1. Centre for Public Health; Queen's University Belfast; Belfast
2. Bamford Centre for Mental health and Wellbeing; Ulster University; Northern Ireland
3. Centre for Evidence and Social Innovation; Queen's University Belfast

Abstract

Background

The health impacts of caregiving and volunteering are rarely studied concurrently, despite the potential for both synergies and conflicts. This population-based study examines the association of these activities on health and subsequent mortality.

Method

A census-based record linkage study of 244,429 people aged sixty-five and over, with cohort characteristics, caregiving and volunteering status, and presence of chronic health conditions derived from the Census returns.

Mortality risk was assessed over the following forty-five months with adjustment for baseline characteristics.

Results

Caregivers and volunteers were individually more mobile than those undertaking neither activity; caregivers who also volunteered were more mobile

than those who did not volunteer, but no less likely to suffer from poor mental health. Both caregiving and volunteering were separately associated with reduced mortality risk (HR=0.74: 95%CI=0.71, 0.77 and HR=0.76: 0.73, 0.81 respectively); the lowest mortality was found amongst light caregivers who also volunteered (HR=0.53: 95%CI 0.45, 0.62), compared to those engaged in neither. There was no evidence of a multiplicative effect of caregiving and volunteering at more intense levels of caregiving.

Conclusion

There is a large overlap in caregiving and volunteering activities with complex associations with health status. There is some evidence that combining caregiving and volunteering activities, for those involved in less intense levels of caregiving, may be associated with lower mortality risk than associated with either activity alone. Further research is needed to understand which aspects of caregiving and volunteering are best and for whom and in which circumstances.

Keywords Caregiving, volunteering, mortality risk

Introduction

Unpaid helping activities (informal caregiving, volunteering) are, for providers, acknowledged as associated with a range of salutogenic effects, including reduced mortality. This relationship has been subject to recent reviews[1-6] and one, a meta-analysis of fourteen studies[3], showed that organisational or formal volunteering reduced the mortality of people aged fifty-five or more by 24% (16-31%). Anderson *et al*[4], in a narrative review qualified this and suggested that while beneficial effects were evident at moderate levels, they may be less apparent at high-intensity levels. There is also continuing debate about who benefits from volunteering and how: does it increase social, physical and mental activity for older people; can it compensate for fewer personal and social resources; or loss of social role; and can it deliver benefits through strengthening altruism[7,8,9]? Alternatively, volunteering may enhance the resources of those with already higher levels of social engagement, such as membership of religious organisations[10].

Advocates of health benefits for informal caregiving have had difficulty changing earlier negative perspectives emphasising burden, stress and purported poor health outcomes[11,12]. Two recent overviews, by Brown & Brown[13] and Roth *et al*[14], have argued for more balance, suggesting that *'policy reports, media portrayals, and many research reports commonly present an overly dire picture'* while ignoring alternative positive findings. It is now recognised that many caregivers report benefit from caregiving[15,16] and population-based mortality studies generally find that caregivers have reduced mortality compared with non-caregivers[17-22].

Although caregiving and volunteering share common features they are often viewed differently, with volunteering seen as active and positive, while informal caregiving (usually less discretionary) carries more obligations, receives less recognition and is often associated with negative health consequences. Furthermore, the literature has generally focused on examination of each separately. Few studies have compared both simultaneously within the same population, and to our knowledge none have directly compared their respective effects on mortality. This may be an important omission, given that there is some ambiguity in the most widely used definitions of volunteering[23,24] and caregiving[25] and the recognition that a significant proportion of people are engaged in both simultaneously[26,27] - with the potential that some of the reduced mortality associated with each separately being partly due to the cross-inclusion of those who engage in both. There is increasing interest in these caregiving-volunteers - so called *super-helpers*[28,29]. Furthermore, as some of the putative mechanisms behind caregiving and volunteering are different this raises the possibility that their effects on mortality may be additive[30]. On the other hand Moen *et al*[31], using concepts of stressors and stress developed by Pearlin[32], suggest that too many roles can offset benefits associated with less onerous commitments and result in worse health outcomes, and there is some evidence from the volunteering literature that health benefits[33,34] and mortality reductions[5,10] are less evident at the most intensive levels of helping.

This study examines the differences in characteristics and health of caregiving and volunteering in the same population, by exploring: (i) the mortality risks associated with each separately and in combination; (ii) and whether the mortality effects were more marked for those older, retired or more religious.

Method

The Northern Ireland Mortality Study (NIMS) is a record-linkage study comprising the census returns for the whole enumerated population and subsequently registered deaths. Details of both NIMS and linkage processes are described elsewhere[35]. For this study the population-at-risk comprised those enumerated in the Northern Ireland 2011 Census, aged sixty-five and over and not living in institutional care, with mortality follow-up from census until December 2014 (forty-five months). Personal characteristics were drawn from the census and selected on the basis of known association with either caregiving or volunteering: these include age, gender and marital status (married, never-married, and – as a single group - widowed, separated or divorced). Religious affiliation was included as religiosity has been associated with both volunteering and its effects, and previous analyses suggest higher levels of religiosity amongst more conservative Christians [36,37]: here six groups, including no affiliation, were classified (Table 1) – while more conservative Christians included smaller Protestant denominations such as Pentecostal or Evangelical groups. Socioeconomic status was assessed using (i) household car availability (two or more cars, one only, no availability); (ii) educational attainment (third-level, intermediate, no qualifications); (iii) economic activity; and finally (iv) a combination of housing tenure and rateable value of the property¹.

¹ Rateable value had been derived as part of an exercise by central government in 2005 to determine the level of local residential tax levels payable for each household, and this data was combined with housing tenure to produce an eight-fold classification of tenure/capital value: private renting; social renting; and, for owner-occupiers, five categories ranging from less than £75,000 to over £200,000 (see table 1), with an additional category for homes as yet unvalued.

Caregiving responsibility was derived from the question: “*Do you look after, or give any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill-health/disability; problems related to old age?*”, with response categories - none; 1-19 hours caregiving weekly; 20-49 hours; or fifty plus. Respondents were instructed not to include anything done as part of paid employment. No census questions related to either the care recipient or the nature of their duties. Another question asked about volunteering: “*In the past year, have you helped with or carried out any voluntary work without pay?*” with yes/no responses (with no further elaboration on the nature of the volunteering).

Health status was based on a range of census questions: “*how is your health in general*” (five responses ranging from *very good* to *very bad*); whether people had a health problem or disability limiting day-to-day activity *a little*, or *a lot*; and a final question detailing specific chronic conditions “*Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?*” – from which four covering a range of physical and mental health problems were selected. These latter included - (i) “*a mobility or dexterity difficulty*” substantially limiting 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 , (iv) “*shortness of breath or difficulty breathing (such as asthma)*”. The mobility and mental health questions were used to assess the health of volunteers and caregivers and all four measures were used to adjust for potential health selection effects.

The main health outcome was risk of all-cause mortality during follow-up.

The resulting data were anonymised, held in a safe setting by the Northern Ireland Statistics and Research Agency (NISRA) and made available to the research team for this study. The use of the NIMS for research was approved by the Office for Research Ethics Committees Northern Ireland (ORECNI).

Analysis strategy

The cohort comprised 244,429 people aged sixty-five and over at census and not living in institutionalised care. Descriptive statistics recorded the socio-demographic characteristics and baseline health status by levels of caregiving and volunteering. Volunteering was relatively infrequent for those undertaking fifty or more hours caregiving per week and for most analyses it was categorised as less intense (less than twenty hours per week) and more (twenty or more)[38].

The relationship between caregiving, volunteering and chronic health problems was examined using logistic regression with adjustment for other factors known to be associated with caregiving and volunteering. The effects of caregiving and volunteering were studied both separately and in combination with interaction tests exploring their mutual association with health. Finally, Cox proportional hazards models examined the relationship between caregiving, volunteering and all-cause mortality. Tests for interaction determined (i) whether the relationship between mortality and caregiving was modified by volunteering

status, and (ii) if their combined effects differed by age, sex, religion, or baseline health status.

Results:

In this cohort 78.7% were neither caregivers nor volunteers, 8.5% volunteers alone, 10.2% caregivers and 2.6% were both, with the majority of caregivers (60.8%) providing twenty or more hours per week. Caregiving intensity and volunteering were inversely related - 12.7% of caregivers providing (intensive) twenty or more hours per week were also volunteers while 32.2% of less intense caregivers were volunteers.

Both caregivers and volunteers were younger than those who were neither - with declining activity with age, and a sharper falloff for volunteering than for caregiving (see supplementary Table A). Women were more likely than men to engage in either role, and more likely to combine them (OR=1.25: 95%CI=1.18, 1.31). A stronger relationship was evident between religion and volunteering than with caregiving, though this was concentrated mainly in the Methodist and more conservative Christian denominations.

All indicators of socio-economic status recorded a positive association with both caregiving and volunteering, with the least affluent least likely to be engaged.

Almost 25% of those living in the most expensive houses were volunteers compared to one in ten social renters. Socioeconomic gradients associated with caregiving were generally mixed and more nuanced, probably because this indicator conflates the pattern for those engaged in less intensive caregiving

(who tend to be more affluent) with the pattern for those providing more intensive levels (maybe less affluent)³⁸. Economic activity was also important: 16.2% of volunteers were full-time or part-time employed, compared to 8.5% for the cohort as a whole.

Health effects:

Health status was strongly associated with volunteering: 21.6% and 17.0% respectively of those who reported *excellent* general health or no activity limitation were volunteers, compared to 4.2% of those reporting a chronic health problem or limiting disability and 1.8% of those who reported general health as *very bad*. The relationship between caregiving and health was different: although caregivers were less likely to report bad or very bad general health, the proportion who reported general health as *very good* was also lower.

Table 1 shows how chronic mobility and mental ill-health problems are predicted by caregiving and volunteering. Logistic regressions suggest that people with either low-intensity caregiving responsibilities or volunteering duties generally reported fewer chronic mobility or mental health problems than those not involved in either, though more intense caregiving was associated with more mobility problems. Increasing caregiving intensity was associated with an increased likelihood of poor mental health. Results suggest an interactive effect between caregiving and volunteering, with persons both caregiving at low intensity and volunteering emerging as the healthiest group.

Mortality risk:

During forty-five months of follow-up there were 32,283 deaths overall - 2,528 to caregivers and 1,528 to volunteers. In fully adjusted models examining caregiving and volunteering separately – not shown - both were associated with reduced mortality compared to their non-involved peers: Hazard Ratio $(HR)_{adj}=0.75$: 95%CI=0.72, 0.78 and $HR_{adj}=0.75$: 0.71, 0.79 respectively. Including both activities produced little change: $HR_{adj}=0.76$: 95%CI=0.72, 0.81 and $HR_{adj}=0.76$: 0.73, 0.79 respectively. A test for interaction between them ($P = 0.361$) indicated separate effects on mortality - in a fully adjusted stratified analysis the mortality associated with *persons both caregiving and volunteering* ($HR_{adj}=0.61$: 95%CI= 0.54, 0.69) was lower than either volunteering only or caregiving only and close to the product of the HRs for both activities separately. The relationship between these caregiving and volunteering activities and mortality was not modified by sex ($P=0.450$), levels of chronic mobility ($P=0.117$), or religious affiliation ($P=1.000$).

Table 2 outlines the mortality analysis. In models M1-M4: all caregiving/volunteering categories recorded lower mortality than the non-involved reference group, with estimates attenuating as the models become more saturated with the differential between less and more intense caregiving evident only amongst volunteers. Amongst those with no caregiving duties, volunteers had 25% lower mortality than those who did not. Non-volunteering caregivers recorded a similar reduction. There was some evidence of

volunteer-caregiver synergy - low intensity caregivers-volunteers recorded the lowest mortality (significantly lower than either less intense caregivers who did not volunteer or non-caregiving volunteers). The wider confidence intervals surrounding the mortality estimates for more intense caregivers who volunteer are in keeping with the relatively smaller size of this group, but the similar HRs and overlapping confidence intervals with those of non-volunteers suggests no additional mortality advantage from volunteering at more intense caregiving levels.

Discussion

While this study supports associations between better health and caregiving and volunteering, its key contributions are that the health effects depend on whether these activities are combined or not, and that the extent of observed benefit depends on the health outcome examined.

In mortality terms, independent protective effects accruing both from caregiving and volunteering are evident. In fully adjusted models, each had an equivalent association with lowered mortality risk, with estimated effects similar to findings in existing meta-analyses of both volunteering[3, 6] and caregiving[17-22].

For health, caregivers were less likely to report mobility problems than non-caregivers which may indicate health selection effects[39,40] and/or benefits of caregiving. Volunteers reported fewer mobility problems than caregivers, and persons both caregiving and volunteering were more mobile than those who did neither. This may reflect the obvious self-selecting nature of volunteering and

necessarily higher activity levels. By contrast, volunteering is associated with a lower likelihood of reported poor mental health but caregivers were no less likely than non-caregivers to report poor mental health. Note that volunteers with more intense caregiving duties had poor mental health levels similar to those who undertook neither activity.

This study provides tentative evidence that those undertaking both activities record lower mortality than either activity separately as volunteering combined with caregiving at less intensive levels was associated with substantially lower mortality risk. This added benefit of volunteering was not evident at more intense caregiving levels, and suggests a natural limit to benefit derivable from such commitments[31] - with those volunteers with lighter caregiving responsibilities operating near that limit. This group experience the optimal blend of activity and flexibility, in contrast to the obligations and pressures inherent in intense caregiving. Alternatively, additional benefit may be possible yet less evident in practice, as fewer of those with the heaviest caregiving responsibilities have the time or resources for volunteering. Conversely, volunteers with lighter caregiving responsibility may benefit both from the bonding associated with caregiving and from the complementary outward-looking social engagement associated with volunteering.

No information was available about the nature of the caregiving relationship, or about the levels of volunteering, thus limiting our understanding of their interrelationship at more intense caregiving levels. The cross-sectional nature of the baseline data limits our examination of possible volunteering-caregiving

pathways. Furthermore, as both caregiving and volunteering activities and health status were measured concurrently residual health selection effects[40,41] remain a possibility, though sensitivity tests adjusting for health status at baseline strongly suggests the reduced mortality risk was not due to healthy worker effects. There may be personality traits associated with reduced mortality risk which partly explain the volunteering-health nexus[42], but these could not be captured using available data.

Although this research suggests that volunteering is associated with additional reductions in mortality for those with less intense caregiving responsibilities, we can't be definitive. We need to understand the complex interplay between the effects of all activities people engage in[8,13,14] and further research is needed to understand for whom, and how, *caregiving and volunteering* activities are beneficial.

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Table 1: Likelihood of having chronic mobility problems or chronic mental health problems, by caregiving and volunteering status. Data represent odds ratios (and 95% Confidence Intervals) from separate logistic regression models

	Chronic health problem	M1: Adjusted for age & sex	M2: M1 + demographic indicators [§]	M3: M2 + socio-economic indicators ^{§§}
Chronic mobility problems				
Helping status				
non-Volunteer				
non-Caregiver (n = 192,251)	40.3% (n = 77,543)	1.00	1.00	1.00
caring=1-19 hours/week (n = 8,334)	29.6% (n = 2,468)	0.70 (0.67, 0.73)	0.74 (0.71, 0.78)	0.80 (0.76, 0.84)
caring=20+ hours (n = 20,815)	37.4% (n = 6,219)	0.96 (0.93, 0.99)	1.03 (1.00, 1.06)	0.97 (0.94, 1.01)
Volunteer				
non-Caregiver (n = 20,815)	19.7% (n = 4,106)	0.41 (0.40, 0.43)	0.42 (0.41, 0.44)	0.52 (0.50, 0.54)
caring=1-19 hours (n = 3,957)	17.1% (n = 675)	0.37 (0.34, 0.40)	0.39 (0.36, 0.42)	0.51 (0.46, 0.55)
caring=20+ hours (n = 2,424)	24.8% (n = 601)	0.57 (0.52, 0.62)	0.61 (0.56, 0.67)	0.69 (0.63, 0.76)
Chronic mental ill-health				
non-Volunteer				
non-Caregiver (n = 192,251)	5.2% (n = 9,987)	1.00	1.00	1.00
caring=1-19 hours/week (n = 8,334)	3.4% (n = 284)	0.59 (0.52, 0.67)	0.66 (0.59, 0.75)	0.74 (0.66, 0.84)
caring=20+ hours (n = 20,815)	5.2% (n = 861)	0.96 (0.89, 1.03)	1.13 (1.05, 1.21)	1.07 (0.99, 1.15)
Volunteer				
non-Caregiver (n = 20,815)	2.3% (n = 489)	0.40 (0.36, 0.44)	0.42 (0.38, 0.46)	0.53 (0.48, 0.58)
caring=1-19 hours (n = 3,957)	2.3% (n = 91)	0.37 (0.30, 0.45)	0.41 (0.33, 0.51)	0.55 (0.45, 0.69)
caring=20+ hours (n = 2,424)	3.6% (n = 87)	0.61 (0.50, 0.76)	0.71 (0.57, 0.88)	0.84 (0.67, 1.04)

[§] adjusted for age, sex, marital status, religious affiliation,

^{§§} as above with further adjustment for housing tenure and value of property, car availability, educational attainment and urban/rural area of residence

Table 2: Mortality risk according to caregiving and volunteering status. Data represent number of deaths and hazard ratios (and 95% Confidence Intervals) from separate Cox proportional hazard models

	Deaths	M1: adjusted for age & sex	M2: M1 + Demographic Factors ^{\$}	M3: M2 + Socio-economic status ^{\$\$}	M4: M3 + Indicators of health ^{\$\$\$}
non-Volunteer					
non-Caregiver (n = 192,251)	14.8% (n = 28,510)	1.00	1.00	1.00	1.00
caring=1-19 hrs/week (n = 8,334)	7.8% (n = 649)	0.61 (0.56, 0.66)	0.64 (0.59, 0.69)	0.67 (0.62, 0.73)	0.75 (0.69, 0.81)
caring=20+ hrs (n = 20,815)	9.6% (n = 1,596)	0.70 (0.66, 0.73)	0.74 (0.71, 0.78)	0.73 (0.69, 0.77)	0.75 (0.71, 0.79)
Volunteer					
non-Caregiver (n = 20,815)	6.0% (n = 1,245)	0.50 (0.47, 0.53)	0.51 (0.48, 0.54)	0.58 (0.55, 0.61)	0.75 (0.71, 0.79)
caring=1-19 hrs (n = 3,957)	3.5% (n = 139)	0.33 (0.28, 0.39)	0.34 (0.29, 0.41)	0.41 (0.34, 0.48)	0.53 (0.45, 0.63)
caring=20+ hrs (n = 2,424)	5.9% (n = 144)	0.51 (0.43, 0.60)	0.54 (0.46, 0.63)	0.59 (0.50, 0.69)	0.70 (0.59, 0.83)

^{\$} adjusted for age, sex, marital status and religious affiliation

^{\$\$} further adjustment for housing tenure/value of property, household car availability, educational attainment and urban/rural area of residence

^{\$\$\$} further adjustment for LLTI, General Health, chronic mental ill-health, chronic mobility, pain and problems with breathing.