

Mental and physical health changes around transitions into unpaid caregiving in the UK: a longitudinal, propensity score analysis



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Summary

Background The health of unpaid caregivers is poorer, on average, than in non-caregivers. There has been little focus on how health changes when becoming a caregiver and whether this varies by age, gender, and caregiving intensity. We aimed to investigate the mental and physical health changes involved with becoming a caregiver and whether these associations varied by gender, caregiving intensity, or age.

Methods This study used data from the UK Household Longitudinal Study (2009–20) to examine mental and physical health changes around the transition to becoming a caregiver in adults aged 16 years and older. We included adults with information on care, complete covariates needed for matching, and at least one measure of health before or after becoming a caregiver (or matched non-caregiver). Health was measured via General Health Questionnaire-12 (GHQ-12, psychological distress) and 12-item Short Form Survey (SF-12, physical and mental functioning). We applied piecewise growth curve modelling with propensity score matching to model trajectories of mental and physical health for caregivers and matched non-caregivers. Analyses were stratified by age group, gender, and caregiving intensity.

Findings Sample sizes varied from 3025 (GHQ-12 analyses in early adulthood) to 5785 (SF-12 analyses in early mid-adulthood). Psychological distress increased during transition to caregiving for all ages, particularly in those younger than 64 years, those providing care for 20 h or more per week, and for someone living within the household. Mental health functioning worsened during caregiving transition for those aged 30–64 years, those providing 20 h or more per week, and for those caring for someone within the household. Physical health functioning did not change but there was evidence of lower levels of functioning before caregiving. Changes in mental and physical health upon transition to caregiving did not differ by gender.

Interpretation Our findings highlight the importance of early identification of and support for caregivers, including younger caregivers. This is important to break the cycle of caregiving and future care need. Health services staff, including general practitioners and hospital discharge teams, are well positioned for early identification of caregivers. We also encourage particular support for the mental health of caregivers and particularly those who become caregivers at a younger age.

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Introduction

An unpaid or informal caregiver is anyone who provides help, without remuneration, to a friend or family member who due to illness, disability, addiction, or mental health problems, cannot cope without this support.¹ Informal, unpaid care provision forms an increasingly important part of care in most countries. The UN estimate that 75–90% of care needs are met by unpaid caregivers.² The provision of unpaid care has important implications for the health of caregivers; several systematic reviews and meta-analyses show that the mental and physical health of unpaid caregivers is poorer than non-caregivers,^{3–5} although it should be noted that some caregivers report positive benefits from caregiving.⁶ However, most of the research into the health of caregivers has been cross-sectional in design.

Moreover, few studies have considered changes in health around the transition to becoming a caregiver. This investigation is important, as it enables us to assess how soon after becoming a caregiver health might be affected, and whether health starts to worsen when individuals transition into caregiving. A US study which matched non-caregiver controls to incident caregivers found increased depressive symptoms and perceived stress following becoming a caregiver.⁷ Lee and Gramotnev⁸ found that Australian women who became caregivers had poorer physical and emotional health both before and after becoming a caregiver, but this study was unable to examine whether health was differentially affected by movement into or maintenance of caregiving roles. Analysis of a European dataset on older adults found that a transition into spousal caregiving resulted in higher frailty.⁹ Caregiver identity theory¹⁰ suggests that

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Research in context

Evidence before this study

We searched titles and abstracts via PubMed on March 6, 2023, from database inception, to find longitudinal studies investigating the health changes around transitioning into unpaid caregiving. Search terms were: (caregiv*) AND (health) AND ((longitudinal) OR (cohort)) AND ((transition*) OR (uptak*) OR (becom*)). Eligible articles were those published in English, from any year, that quantified the mental or physical health changes around becoming an unpaid, informal caregiver in a general population sample. Ten longitudinal studies were identified, which assessed changes in health upon becoming an unpaid caregiver in a general population sample. Studies included populations in China, Germany, England, the USA, and a cross-European dataset. All except one study focused solely on people aged 45 years and older. Two studies assessed physical health effects in older caregivers (age 65 years and older).

Added value of this study

This study provides high-quality longitudinal data on whether becoming a caregiver affects mental and physical health.

We were also able to compare caregiving transitions from early adulthood (age 16–29 years) onwards—the first study to do so—as well as by gender and caregiving intensity in a representative UK household panel study. Results suggest that mental health worsens upon becoming an unpaid caregiver. This is particularly the case for those providing the most intense levels of care and includes those providing care in earlier stages of adulthood.

Implications of all the available evidence

Our findings suggest that increasing awareness of caregivers and early identification and provision of support to caregivers to prevent mental health effects is important. Health services staff (eg, general practitioners and hospital discharge teams), are well positioned to identify caregivers. Our findings also point to the greater need for awareness of younger caregivers in research, practice, and policy, as their mental health was also affected by the onset of the caregiving role.

the changes in the health of caregivers around caregiver transition might not be clear-cut. Stage one of caregiver identity theory is role onset, in which the caregiver starts providing care but does not identify as a caregiver. The second stage is when the caregiver acknowledges that their activities go beyond the usual familial role and self-identify as a caregiver. Therefore, it is possible that health might begin to be affected in stage one.

The health effects of becoming a caregiver are not uniform. Although most research has focused on caregiving in mid-life and beyond,¹¹ evidence has suggested that when people become caregivers their health is likely to be influenced.¹² Early adult caregivers form an important group of caregivers.¹³ There has been no previous comparison by age of physical and mental health around the transition to caregiving and it is likely that becoming a caregiver in earlier stages of adulthood, when it is less normative,¹² is associated with poorer health than in older age. Regarding gender and caregiving intensity, previous analyses¹⁴ tend to suggest that women who became caregivers and those providing high-intensity care were more likely to experience psychological distress and functional decline than men.¹⁵ Therefore, when investigating changes in health regarding caregiving transition, differences by gender, age, and caregiving intensity are expected.

The aim of this study was to investigate the mental and physical health changes involved with becoming a caregiver and whether these associations varied by gender, caregiving intensity, or age group within a large, representative, longitudinal study. We focused on the initial caregiver transition, as this is likely to require the

most adaptation and has the greatest potential to influence health.¹⁶ Our hypotheses were that mental and physical health would decline shortly after a transition to becoming a caregiver compared with non-caregivers, and that this decline would be more pronounced for women and for young adults. Among caregivers only, caregivers who transition to providing more intense caregiving hours and living with the care recipient would have worsening mental and physical health than would caregivers who provided fewer caregiving hours and did not live with the care recipient.

Methods

Study design, data, and participants

This study used data from the UK Household Longitudinal Study (UKHLS)—a nationally representative study of UK households.¹⁷ The study began in 2009 with approximately 40 000 households recruited via a stratified, clustered probability sampling design. All adults aged 16 years and older in each household are interviewed annually. This study uses information from waves 1 to 10 (2009–20). Response rates for the study remain high over time (eg, 68.2% of eligible adults provided a full interview at wave 10).¹⁸ UKHLS participants provided oral informed consent and the study received ethical approval from the Ethics Committee of the University of Essex. Data are available via the UK Data Service.

Procedures

In each survey, participants were assessed on their caregiving status and the associated intensity of any caregiving. Participants were asked whether they “provide

some regular service or help for any sick, disabled, or elderly person not living with you” and in an equivalent question whether they do so for someone living with them. We derived a binary caregiver status variable (no or yes). Regarding caregiving intensity, two aspects were included—caregiving within or outside of the household (using information from the two caregiving questions) and the number of hours of care provided per week. For the amount of care provided per week, information was collected as 0–4 h, 5–9 h, 10–19 h, 20–34 h, 35–49 h, 50–99 h, or 100 or more h per week. Those caring for 20 or more h per week were combined into one group due to the small sample size. For additional contextual information we also derived measures of the number of people caregivers provide care to (one, two, or three or more people), the duration of caregiving (number of waves caregiving reported in: 1, 2, 3, or 4 or more) and care recipient (including parent, grandparent or non-relative).

Two health measures were included as outcomes, covering mental and physical health. The General Health Questionnaire-12 (GHQ-12) is a validated and widely used measure of psychological distress,¹⁹ with the total score ranging from 0 to 36 (higher scores represent more psychological distress). The 12-item Short Form Survey (SF-12)²⁰ was split into a Physical Component Summary and Mental Component Summary (PCS and MCS), each with scores ranging from 0 to 100 via a standard norm-based algorithm (higher scores represent better health functioning). All three outcomes were retained in continuous form.

Covariates included age, gender (worded as sex in the questionnaire and self-reported by participants), ethnicity, household income, occupational social class, employment status, partnership status, number of dependent children in the household, parental occupational class, urbanicity, educational attainment, and total number of waves the cohort member participated in (appendix p 2). All covariates were taken from baseline (ie, the first wave the study member was observed).

Statistical analysis

Four age groups were defined for the analyses based on life stage: early adulthood (16–29 years), early mid-adulthood (30–49 years), later mid-adulthood (50–64 years), and later life (65 years and older). These were treated as separate datasets for the propensity score matching and subsequent analyses.

We aimed to understand health changes around becoming a caregiver by assessing participants’ health trajectories before, during, and after the onset of caregiving. We used propensity score matching to match each caregiver with up to two non-caregivers with similar characteristics (based on the aforementioned covariates) to adjust for pre-caregiving differences. We performed a 1:2 nearest neighbour matching algorithm. After propensity score matching, caregiver’s wave of onset was applied to their matched non-caregiver.

We employed linear regression modelling to model average trajectories in physical and mental health before, during, and after becoming a caregiver, with trajectories centred on the transition into caregiving or the matched caregiving transition for non-caregivers. We showed physical and mental health trajectories up to 8 years before (years –8 to –1), during (year –1 to 0), and 8 years after caregiver transition (years 1 to 8). As we had a maximum of 10 years of data, we can model health trajectories up to 9 years before and after caregiver transition, but there were very few observations at year –9 and year 9, thus these years were excluded from models. In the model, year was used as the timescale, regressed on each health outcome. Household identification was used as a cluster. We predicted the health trajectories using average marginal effects (ie, mean of predicted outcome) at each year with 95% CI. We showed the trajectories using binary caregiver status stratified by age group and health outcomes.

Descriptives of the study sample are presented as actual values and percentages.

To statistically test the changes in health trajectory during caregiving transition, we employed piecewise growth curve modelling. The health trajectory was partitioned into three segments (–8 to –1; –1 to 0 (transition to caregiving); 1 to 8 years), with turning points at years –1 and 0. We then tested interactions between care status and slope changes during caregiving transition to observe whether the changes differed between caregivers and non-caregivers.

We tested gender differences by three-way interactions between gender, caregiver status, and slope change. We tested the difference in care intensity (hours and location) among caregivers only and tested the interaction between care hours per location and slope change.

Each age group dataset was constructed by pooling all age-eligible adults across waves 1 to 10, who had the caregiving status variable observed in at least one wave within that age range. To assess the transition into caregiving we excluded participants who provided care in a previous age group. We applied maximum likelihood estimation in our modelling, which allowed us to retain participants who had at least one health measure pre-caregiver and post-caregiver transition. Finally, we excluded participants with missing data on baseline health and covariates essential for the propensity score matching. All analyses were done with Stata (version 17).

See Online for appendix

Role of the funding source

The funder played no role in the study design, data collection, data analysis, data interpretation, writing of the report, or the decision to submit this work for publication.

Results

Final sample sizes range from 3025 for early adulthood GHQ-12 analyses to 5785 for early mid-adult SF-12

	Early adulthood caregivers (age 16–29 years)			Early mid-adulthood caregivers (age 30–49 years)			Late mid-adulthood caregivers (age 50–64 years)			Later life caregivers (age 65 years and older)		
	Men (n=728)*	Women (n=1065)†	Total (n=1793)‡	Men (n=1510)*	Women (n=2556)†	Total (n=4066)‡	Men (n=1486)*	Women (n=1937)†	Total (n=3423)‡	Men (n=1279)*	Women (n=1497)†	Total (n=2776)‡
Became a caregiver§	1880 (14.4%)	2599 (18.3%)	4479 (16.5%)	3384 (21.7%)	5516 (31.2%)	8900 (26.8%)	3267 (31.7%)	4570 (41.4%)	7837 (36.7%)	2528 (33.1%)	2922 (33.8%)	5450 (33.5%)
Time spent caregiving, h per week¶												
Less than 5	408 (56.0%)	492 (46.2%)	900 (50.2%)	829 (54.9%)	1166 (45.6%)	1995 (49.1%)	845 (56.9%)	912 (47.1%)	1757 (51.3%)	601 (47.0%)	703 (47.0%)	1304 (47.0%)
5–9	139 (19.1%)	207 (19.4%)	346 (19.3%)	253 (16.8%)	470 (18.4%)	723 (17.8%)	266 (17.9%)	419 (21.6%)	685 (20.0%)	210 (16.4%)	235 (15.7%)	445 (16.0%)
10–19	93 (12.8%)	147 (13.8%)	240 (13.4%)	198 (13.1%)	350 (13.7%)	548 (13.5%)	171 (11.5%)	285 (14.7%)	456 (13.3%)	166 (13.0%)	197 (13.2%)	363 (13.1%)
20–34	51 (7.0%)	96 (9.0%)	147 (8.2%)	115 (7.6%)	243 (9.5%)	358 (8.8%)	113 (7.6%)	174 (9.0%)	287 (8.4%)	141 (11.0%)	136 (9.1%)	277 (10.0%)
35 or more	37 (5.1%)	123 (11.5%)	160 (8.9%)	115 (7.6%)	327 (12.8%)	442 (10.9%)	91 (6.1%)	147 (7.6%)	238 (7.0%)	161 (12.6%)	226 (15.1%)	387 (13.9%)
Care location												
Inside household	321 (44.1%)	363 (34.1%)	684 (38.1%)	397 (26.3%)	511 (20.0%)	908 (22.3%)	302 (20.3%)	291 (15.0%)	593 (17.3%)	461 (36.0%)	519 (34.7%)	980 (35.3%)
Outside household	341 (46.8%)	593 (55.7%)	934 (52.1%)	968 (64.1%)	1786 (69.9%)	2754 (67.7%)	1064 (71.6%)	1458 (75.3%)	2522 (73.7%)	668 (52.2%)	807 (53.9%)	1475 (53.1%)
Inside and outside	66 (9.1%)	109 (10.2%)	175 (9.8%)	145 (9.6%)	259 (10.1%)	404 (9.9%)	120 (8.1%)	188 (9.7%)	308 (9.0%)	150 (11.7%)	171 (11.4%)	321 (11.6%)
Number of people caregiver provides care for												
1	703 (96.6%)	1022 (96.0%)	1725 (96.2%)	1452 (96.2%)	2398 (93.8%)	3850 (94.7%)	1396 (93.9%)	1780 (91.9%)	3176 (92.8%)	1212 (94.8%)	1439 (96.1%)	2651 (95.5%)
2	20 (2.7%)	31 (2.9%)	51 (2.8%)	47 (3.1%)	135 (5.3%)	182 (4.5%)	71 (4.8%)	138 (7.1%)	209 (6.1%)	47 (3.7%)	42 (2.8%)	89 (3.2%)
3 or more	5 (0.7%)	12 (1.1%)	17 (0.9%)	11 (0.7%)	23 (0.9%)	34 (0.8%)	19 (1.3%)	19 (1.0%)	38 (1.1%)	20 (1.6%)	16 (1.1%)	36 (1.3%)
Care recipient												
Parent	281 (38.6%)	398 (37.4%)	679 (37.9%)	758 (50.2%)	1370 (53.6%)	2128 (52.3%)	794 (53.4%)	1038 (53.6%)	1832 (53.5%)	175 (13.7%)	77 (5.1%)	252 (9.1%)
Grandparent	270 (37.1%)	379 (35.6%)	649 (36.2%)	107 (7.1%)	228 (8.9%)	335 (8.2%)	6 (0.4%)	5 (0.3%)	11 (0.3%)	0	1 (0.1%)	1 (<0.1%)
Partner (inside household only)	36 (4.9%)	45 (4.2%)	81 (4.5%)	236 (15.6%)	215 (8.4%)	451 (11.1%)	265 (17.8%)	292 (15.1%)	557 (16.3%)	569 (44.5%)	632 (42.2%)	1201 (43.3%)
Sibling (inside household only)	43 (5.9%)	55 (5.2%)	98 (5.5%)	8 (0.5%)	14 (0.5%)	22 (0.5%)	6 (0.4%)	5 (0.3%)	11 (0.3%)	11 (0.9%)	13 (0.9%)	24 (0.9%)
Child (inside household only)	20 (2.7%)	67 (6.3%)	87 (4.9%)	196 (13.0%)	430 (16.8%)	626 (15.4%)	66 (4.4%)	99 (5.1%)	165 (4.8%)	24 (1.9%)	31 (2.1)	55 (2.0%)
Other relative	54 (7.4%)	117 (11.0%)	171 (9.5%)	147 (9.7%)	297 (11.6%)	444 (10.9%)	172 (11.6%)	278 (14.4%)	450 (13.1%)	209 (16.3%)	215 (14.4%)	424 (15.3%)
Other non-relative	93 (12.8%)	152 (14.3%)	245 (13.7%)	235 (15.6%)	468 (18.3%)	703 (17.3%)	252 (17.0%)	413 (21.3%)	665 (19.4%)	387 (30.3%)	380 (25.4%)	767 (27.6%)
Duration of caregiving, years												
1	486 (66.8%)	625 (58.7%)	1111 (62.0%)	768 (50.9%)	1237 (48.4%)	2005 (49.3%)	698 (47.0%)	789 (40.7%)	1487 (43.4%)	604 (47.2%)	736 (49.2%)	1340 (48.3%)
2	128 (17.6%)	217 (20.4%)	345 (19.2%)	346 (22.9%)	491 (19.2%)	837 (20.6%)	323 (21.7%)	415 (21.4%)	738 (21.6%)	278 (21.7%)	313 (20.9%)	591 (21.3%)
3	55 (7.6%)	117 (11.0%)	172 (9.6%)	161 (10.7%)	282 (11.0%)	443 (10.9%)	166 (11.2%)	244 (12.6%)	410 (12.0%)	179 (14.0%)	169 (11.3%)	348 (12.5%)
4 or more	59 (8.1%)	106 (10.0%)	165 (9.2%)	235 (15.6%)	546 (21.4%)	781 (19.2%)	299 (20.1%)	489 (25.2%)	788 (23.0%)	218 (17.0%)	279 (18.6%)	497 (17.9%)

Table: Caregiving characteristics for caregivers in each age group, stratified by gender

Data are n (%). All caregiving characteristics were generated using the information across all caregiving waves. All information presented relates to observations rather than observations. GHQ=General Health Questionnaire. SF-12=12-item Short Form Survey. *n from those who have either GHQ or SF-12 propensity score; only male caregivers were included. †n from those who have either GHQ or SF-12 propensity score; only female caregivers were included. ‡n from those who have either GHQ or SF-12 propensity score; all caregivers were included. §Prevalence of becoming a caregiver among the whole age eligible sample rather than the propensity score sample. Denominators for sample for each age group are: 16–29 years (total, 27 209); men, 13 028; women, 14 181; 30–49 years (total, 33 229); men, 15 572; women, 17 657; 50–64 years (total, 21 348); men, 10 305; women, 11 043; 65 years and older (total, 16 286); men, 7 637; women, 8 649). Denominators calculated from appendix (p 3) from row “Yes/no caregiver after excluding caregivers in prior age group” by summing No + Yes. ¶Full response categories shown for information but were collapsed to <5-, 5–9, 10–19, and 20 or more h per week for analyses. ||A sibling, partner, or child recipient was only asked about for caregivers who were caring for someone in the same household as themselves. Other care recipient types were combined for caregivers caring for someone inside or outside of the household.



Figure 1: GHQ-12 trajectories before and after becoming a caregiver, stratified by age group

(A) GHQ trajectories before and after caregiver transition by age group and caregiver status (yes or no). (B) GHQ trajectories before and after caregiver transition by age group and gender. (C) GHQ trajectories before and after caregiver transition by age group and caregiving intensity (h per week). (D) GHQ trajectories before and after caregiver transition by age group and care location (inside or outside the household). Dotted vertical lines delineate the transition to caregiving from -1 year to 0 years; higher scores represent more psychological distress. GHQ=General Health Questionnaire-12.

analyses. The process of sample selection for each age group and outcome is presented in the appendix (p 3).

The characteristics of the study sample at baseline are presented in the appendix (pp 4–5). Caregiving characteristics for caregivers in each age group, stratified by gender are presented in the table. As expected, a greater proportion of people became caregivers with increasing age (early adulthood, 4479 [16.5%] of 27209; later life, 5450 [33.5%] of 16286) and there were more women than men caregivers in every age group, with a higher percentage of caregivers in later life (table).

GHQ-12 trajectories before and after caregiving transitions are shown in figure 1. Caregivers reported a

significant increase in psychological distress symptoms upon becoming a caregiver, compared with non-caregivers (appendix p 7). This was the case in all age groups: in those aged 16–29 years (0.37 [95% CI 0.01–0.72] points higher in caregivers than in non-caregivers), 30–49 years (0.39 [0.15–0.63]), and 50–64 years (0.39 [0.16–0.61]). The predicted mean GHQ-12 scores in each year are shown in the appendix (p 11). Post-transition trajectories were different from non-caregivers for all age groups, except those aged 16–29 years. Among early mid-adulthood caregivers, GHQ-12 scores remained higher than non-caregivers for several years following a transition into caregiving.

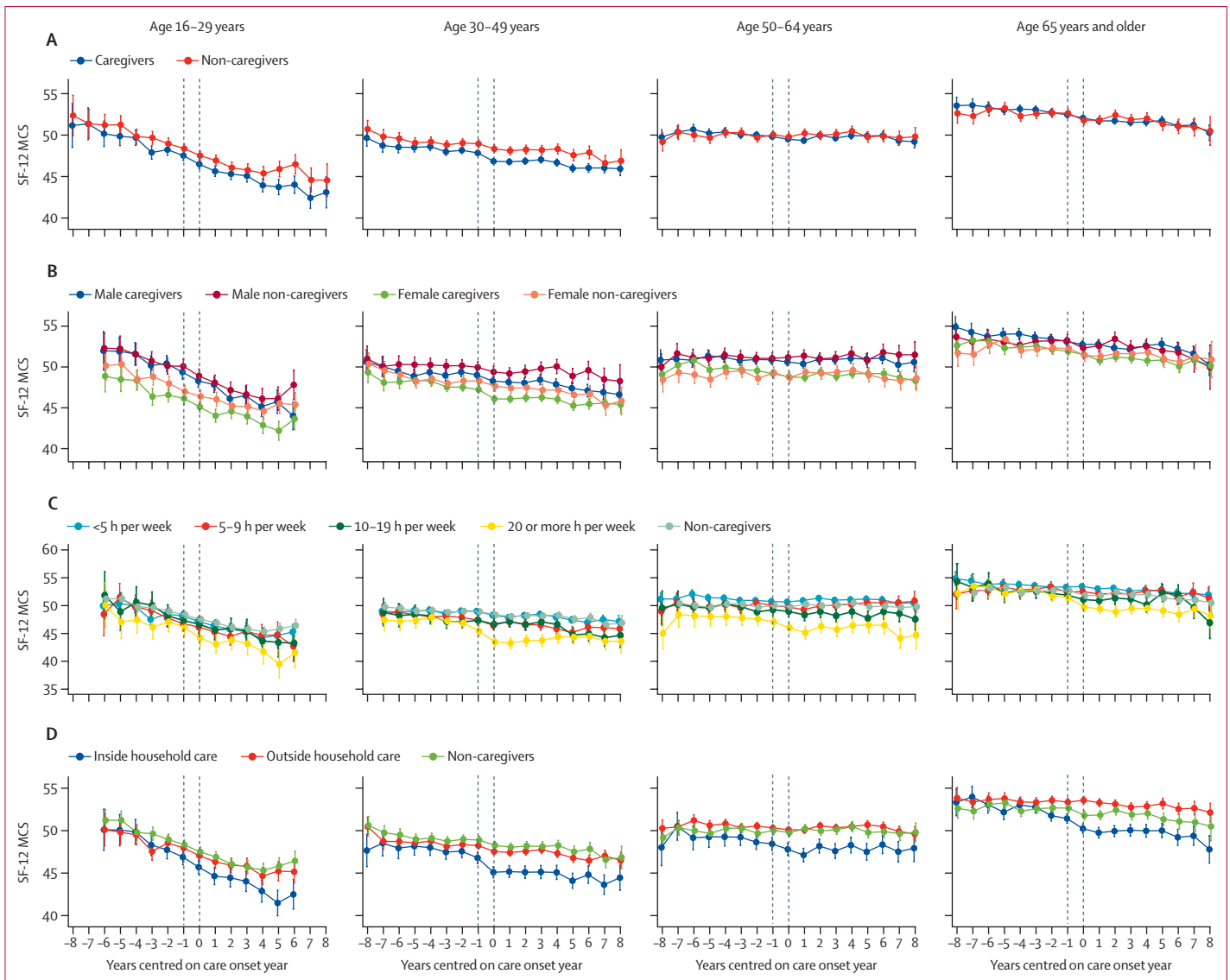


Figure 2: SF-12 MCS trajectories before and after becoming a caregiver, stratified by age group
 (A) SF-12 MCS trajectories before and after caregiver transition by age group and caregiver status (yes or no). (B) SF-12 MCS trajectories before and after caregiver transition by age group and gender. (C) SF-12 MCS trajectories before and after caregiver transition by age group and caregiving intensity (h per week). (D) SF-12 MCS trajectories before and after caregiver transition by age group and care location (inside or outside household). Dotted vertical lines delineate the transition to caregiving from -1 year to 0 years; lower scores represent lower mental health functioning. SF-12=12-item Short Form Survey. MCS=Mental Component Summary.

The increase in GHQ-12 scores following a transition to unpaid caregiving was similar for men and women caregivers in all age groups (figure 1B; appendix p 7). For women who became caregivers in early adulthood, GHQ-12 score increased during the transition to caregiving and the differences in scores relative to non-caregivers were maintained for about 3 years. In early mid-adulthood, women who became caregivers had GHQ-12 scores which differed from female non-caregivers from about 2 years before caregiving transition. The difference in GHQ-12 scores between female caregivers and non-caregivers differed for several years following caregiving transition.

Data by number of hours of care provided per week are stratified in figure 1C. The results show that across age groups (except early adulthood), the increase in GHQ-12 scores at the transition to caregiving is heightened among those caregivers providing 20 h or more of care per week (appendix p 7). Additionally, the increase in GHQ-12 scores during a transition to caregiving for 10–19 h of care per week in later mid-adulthood was significantly raised compared with transitioning into caregiving for less than 5 h per week in later mid-adulthood (0.49 [95% CI 0.08 to 0.91]). In relation to caregiving location, transitions into caregiving within the household were associated with raised GHQ-12 scores

compared with transitions into caregiving outside of the household (figure 1D; appendix p 8). For all age groups except early adulthood, the subsequent trajectories in GHQ-12 for caregivers providing care within their household were significantly different for several years following caregiver transition (eg, 30–49 years, -0.83 [95% CI -1.18 to -0.48). In early mid-adulthood and later mid-adulthood caregivers, there was evidence of divergence in GHQ-12 scores relative to within-household caregivers and non-caregivers in the 2 years before caregiver transition (figure 1D).

SF-12 MCS score trajectories before and after caregiving transition are presented in figure 2. Mental health functioning declined during the transition to caregiving for adults aged 30–49 years (-0.54 [95% CI -0.95 to -0.13) and 50–64 years (-0.46 [-0.84 to -0.07]; figure 2A; appendix p 8). Mental health for early adulthood caregivers ($p=0.83$) and later life caregivers ($p=0.45$) did not differ significantly from their non-caregiving peers during this transition. Changes in mental health functioning did not differ by gender (figure 2B), although there was some suggestion that the post-caregiving trajectory for female early mid-adulthood caregivers declined more than for male caregivers of the same age (appendix p 8).

With respect to caregiving hours, a transition into caregiving for 20 h per week or more was associated with a particular decline in mental functioning in all age groups except early adulthood ($p=0.10$; figure 2C; appendix pp 8–9). Also, the post-transition trajectory in mental health functioning was different in those providing 20 h per week or more compared with those providing care for less than 5 h per week in caregivers aged 30 years and older. This was particularly the case in caregivers aged 30–49 years. In later life caregivers, a transition into providing care for 10–19 h per week was accompanied by a decline in mental health functioning (-0.96 [95% CI -1.76 to -0.16]) and steeper post-transition declines in mental health (appendix p 9). Looking at caregiving location, transitions into within-household caregiving were associated with a decline in mental health functioning compared with those providing care outside the household (figure 2D). Post-transition trajectories into within-household caregiving were accompanied by steeper declines in mental health functioning than for caregivers providing care outside the household which persisted for many years. This was the case for all age groups except those aged 16–29 years (appendix p 9).

The SF-12 PCS score trajectories before and after caregiving transition are presented in figure 3. Becoming a caregiver was not associated with change in physical health functioning in any age group (figure 3A; appendix p 9), although early adult and early mid-adult caregivers had lower PCS scores than non-caregivers across most of the study period. There were no differences in physical health functioning around caregiving transition by gender (figure 3B; appendix p 10). For women, there was

evidence that those who became caregivers in early or early mid-adulthood had lower levels of physical health functioning before becoming a caregiver, than did women who did not become caregivers. Regarding caregiving hours, in all age groups, physical health functioning was lower in people before they became caregivers (figure 3C). In older adult caregivers, there was a small but significant physical health decline in those providing care for 20 h per week compared with those providing care for less than 5 h per week. In all age groups, PCS scores were lower before becoming a caregiver in those who would go on to provide 20 h or more of care per week. Finally, physical health functioning in within-household caregivers was lower than in non-caregivers but there was no statistical evidence that physical health functioning changed around the transition to caregiving (figure 3D; appendix p 10).

Discussion

Consistent with our hypotheses, we found that mental health worsened around the time of becoming a caregiver. This is consistent with previous work, demonstrating increases in depressive symptoms,⁹ emotional health,⁸ and psychological distress.¹⁴ Here we extended this work to evaluate mental health by age groups, finding that psychological distress declined most for caregivers aged 16–29 years and 30–49 years, and mental health functioning declined most for those aged 30–64 years, partly consistent with our hypothesis. Furthermore, in all age groups except 16–29 years, poorer mental health persisted for several years following becoming a caregiver. Becoming a caregiver in earlier stages of adulthood is less normative,¹² and probably coincides with the adoption of other important social roles, such as becoming a parent and partnerships, as well as completing education and establishing oneself in the labour market. Becoming a caregiver in this life stage might therefore result in role strain and substantial time constraints.^{21,22} Furthermore, early and early mid-adult caregivers in our data were most likely to be caring for a parent, and this transition to caregiver might represent the point of role reversal.²³

Furthermore, within caregivers, we found that a transition to intense caregiving was linked to the greatest increases in mental health scores. This finding was consistent with previous analyses of the British Household Panel Study.¹⁴ In this study, we demonstrated that this was the case across all age groups, except for early adulthood. Similar to Hirst's findings,¹⁴ we found that the mental health changes persisted for several years following caregiver transition. In the present study, we demonstrated that there was some divergence in mental health among women in early mid-adulthood before formal transition into caregiving, which probably represents delays in identifying oneself as a caregiver. According to Montgomery and colleagues,¹⁰ phase one of

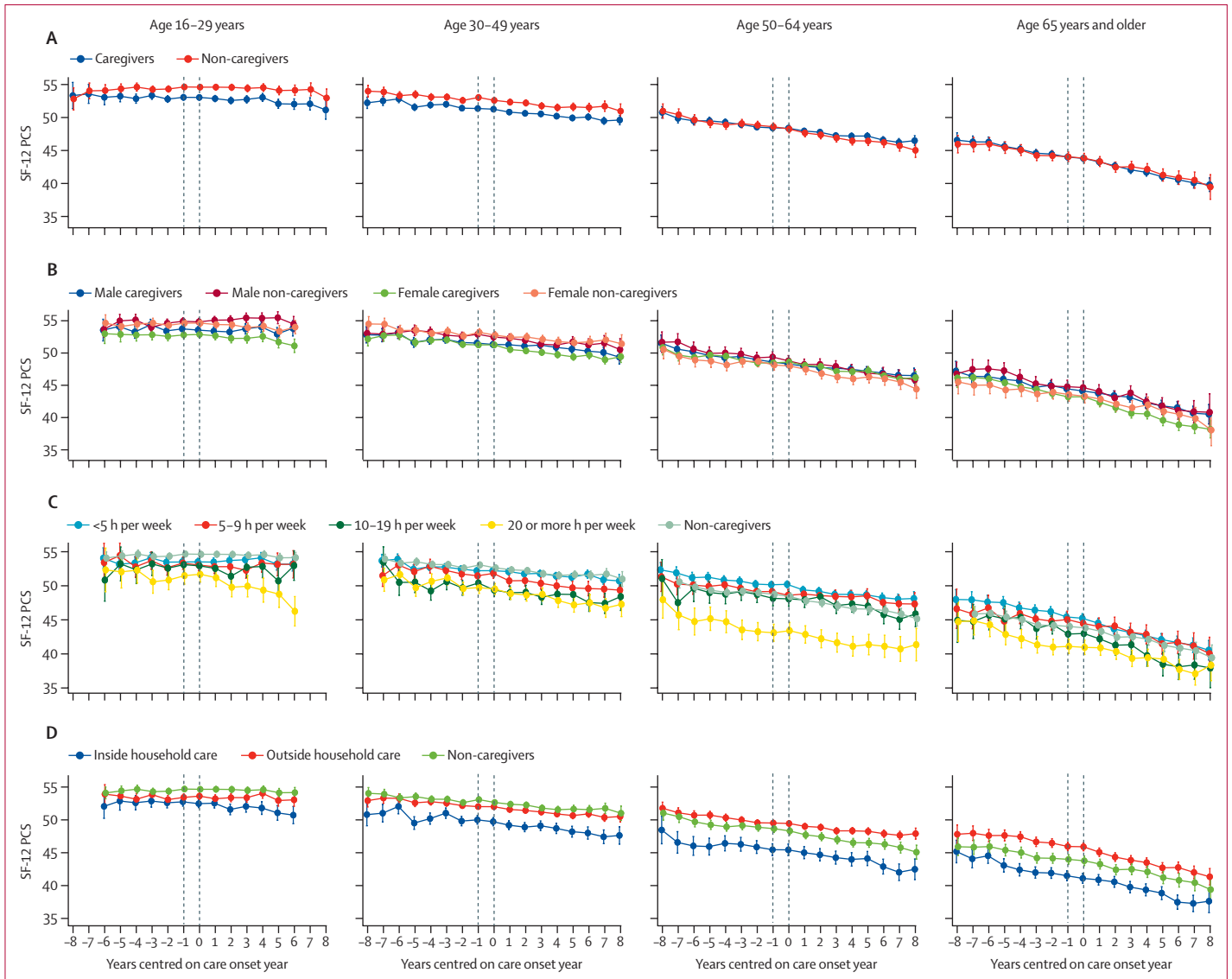


Figure 3: Associations between transition into caregiving and SF-12 PCS score, stratified by age group
 (A) SF-12 PCS trajectories before and after caregiver transition by age group and carer status (yes or no). (B) SF-12 PCS trajectories before and after caregiver transition by age group and gender. (C) SF-12 PCS trajectories before and after caregiver transition by age group and care intensity (h per week). (D) SF-12 PCS trajectories before and after caregiver transition by age group and care location (inside or outside household). Dotted vertical lines delineate the transition to caregiving from -1 year to 0 years; lower scores represent lower physical health functioning. SF-12=12-item Short Form Survey. PCS=Physical Component Summary.

the so-called caregiving career is role onset in which the caregiver begins to provide assistance but does not self-identify as a caregiver (potentially identified in our study in the years preceding caregiver transition). Phase two is when the caregiver acknowledges that their activities go beyond the usual familial role and self-identify as a caregiver (the caregiver transition in our study). An alternative explanation for pre-caregiving changes in health is that people are affected negatively by the illness of the care recipient when they are not caregivers.²⁴

In the present study, we saw less evidence of changes in physical health after caregiver transition than in non-caregivers, although we found that older caregivers

transitioning into intense caregiving had a sharper decline in physical health relative to non-caregivers in this age group. Previous studies on caregiving transitions and physical health have only focused on older adults,¹⁵ and no previous study has looked at change in physical health around the transition to becoming a caregiver in younger ages. Furthermore, our analyses showed that caregivers of all ages had lower levels of physical functioning before the transition was made to caregiving. This might potentially represent selection into caregiving of people who had poorer previous physical health. We did not account for baseline differences in health status in our analyses as we focused on health trajectories. Therefore, it is possible that

there were some initial differences in health status at baseline.^{25,26}

This study has several strengths. First, we used a large, UK-representative household panel study—the UKHLS. This allowed us to consider a UK-wide view of changes in the physical and mental health of caregivers up to 8 years before and following becoming a caregiver—one of the longest-term assessments to date. Second, this sample included information on adults aged 16 years and older, rather than being isolated to mid-life and beyond. This allowed us to compare changes in health around becoming a caregiver at four stages of adulthood and, to our knowledge, was the first study to do so. Third, we applied propensity score matching to allow us to match caregivers to non-caregivers with similar non-health characteristics at baseline, thus increasing our ability to reduce baseline confounding.

This study also had some limitations. First, we did not have a sufficiently large sample size to look at transitions into caregiving for specific care recipients nor could we look at caregiving intensity by gender in each age group. Health changes in the caregiver might differ depending on who the care recipient was in relation to the caregiver^{14,27} and caregiving intensity effects might also differ by gender,¹⁴ but these investigations require a larger sample size. Second, we assumed that the first care transition is the first one observed during the survey period; however, a first transition might have occurred before study participation. This is a problem for most studies looking at exposures and outcomes as there is often no information on the exposures before the study period. Third, we had no information on the care activities provided nor any information on who else supported the care recipient (paid or unpaid) or whether the caregiver sought support from a carer organisation. These factors would be likely to lead to differences in the health of the caregiver. Fourth, we were not able to disentangle caregiving effects from the stress of having a loved one with an illness or care need. Fifth, we looked at average trajectories and while these show that there is a decline in health upon becoming a caregiver, there will be some individuals for whom caregiving is a positive experience. Sixth, we excluded some people who did not have information on our covariates and who were missing health measures across waves. Examining the characteristics of the UKHLS sample across waves shows that caregiving has remained relatively static, but the socioeconomic make up shifted slightly towards participants with higher degrees, and professional or managerial occupations over time (appendix p 15). However, when we longitudinally assessed the data by caregiving status, wave 1 caregivers were more likely than were non-caregivers to still be in the UKHLS study (41.4% of wave 1 caregivers vs 35.7% of wave 10 caregivers). We speculate that caregivers in wave 1 were more readily available at home for interview or were more willing to share their experiences. Finally, we used

propensity score matching to match on potential confounders at baseline, but the findings could be influenced by residual confounding at baseline or by time-varying confounding.

In summary, we found changes in mental health around the transition to caregiving. These health differences were most pronounced for those providing more hours of care, and for carers who were living with the care recipient. Mental health changes were most notable for caregivers younger than 65 years and persisted for several years following becoming a caregiver. We saw that the physical health of caregivers was poorer several years before becoming a caregiver.

Our findings point towards the importance of increasing awareness of caregivers and consequently early identification and provision of support to caregivers, to prevent longer-term mental health influences. Health services staff, such as general practitioners and hospital discharge teams, play an important role in carer identification. Furthermore, an individual's status as a caregiver should be noted on their health record, as is now the case in UK primary care. This can help remind and facilitate health practitioners to have conversations about the health of caregivers (in addition to the care recipient) and whether they are coping with their responsibilities. This could help break the cycle of caregiving and future care need. Finally, our findings highlight that the health of younger caregivers is also important and that becoming a carer is not an experience that is limited to older ages. Awareness of younger caregivers is increasing in many, but not all, countries; however, even in the UK where there is greater recognition of younger caregivers, their mental health is still affected.

Contributors

REL, BX, GDG, and AM conceptualised and designed the study. BX analysed the data with input from WL. REL and BX directly accessed and verified the underlying data reported in this manuscript. REL drafted the manuscript for publication. All authors approved the final draft, had full access to all data in the study, and accept responsibility to submit for publication.

Declaration of interests

We declare no competing interests.

Data sharing

UK Household Longitudinal Study (UKHLS) data are available to download via the UK Data Service: <https://ukdataservice.ac.uk/>. Information on all data collected in the UKHLS study is available on the study website: <https://www.understandingsociety.ac.uk/>. The statistical code for this study is available at: <https://github.com/reblacey/UKHLSaringhealth.git>.

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