





# BMJ Open Factors associated with carer psychological and physical health during end-of-life caregiving: an observational analysis of a population-based post-bereavement survey of carers of people with cancer

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## ABSTRACT

**Objective** Family caregivers play an essential role in end-of-life care but suffer considerable impact on their own health. A better understanding of main factors related to carers' health is important to inform interventions.

The purpose of the study was to test for the first time the potential impact of a comprehensive set of observable variables on carer health during end-of-life caregiving within a population-based carer sample.

**Design** National retrospective, cross-sectional, 4-month post-bereavement postal census survey of family carers of people who died from cancer.

**Setting and participants** Relatives who registered a death from cancer during a 2-week period in England were identified from death certificates by the Office of National Statistics; response rate was 1504/5271 (28.5%).

**Outcome measures** Carers' mental health was measured through General Health Questionnaire (GHQ)-12; general health was measured through EuroQoL EQ-Visual Analogue Scale (EQ-5D VAS).

**Methods** Survey questions to measure potential variables associated with carer health were based on past research and covered patients' symptoms and functioning; caregiving activities and hours; informal and formal help received; work hours, other caregiving, volunteering; changes to work, income and expenditure; sleep and relaxation; and demographic variables. Bivariate analyses and ordinary least square regression were performed to investigate these variables' relationship with outcomes.

**Results** Patients' psychological symptoms and functioning, caregiving hours, female gender and self-sought formal help related to worse mental health. General practitioner and social care input and relaxation related to better mental health. Patients' psychological symptoms, caregiving hours and female gender were associated with worse general health, and older age, employment and relaxation were associated with better general health.

**Conclusions** Improvements in carers' health overall may be made by focusing on potential impacts of patients' psychological symptoms on carers, facilitating respite

## Strengths and limitations of this study

- This is the first study to test a comprehensive set of observable factors related to carer health in previous research with a population-based sample of end-of-life carers.
- Retrospective measurement can raise concerns about accuracy of recall, but the similarity of findings between this retrospective study and previous research lends credibility to results obtained by this method.
- Retrospective, post-bereavement data collection is often the only realistic means of gaining carer perspectives on the months leading up to death from a large, general sample, both due to the difficulty of predicting when someone is in the last months of life and to the distress associated with this period.

and relaxation, and paying particular attention to factors affecting female carers.

## BACKGROUND

Family members, friends and neighbours (hereafter referred to as 'carers') play a vital role in supporting patients towards end of life. Patient preferences<sup>1</sup> and government policies<sup>2</sup> indicate the importance of increasing end-of-life care at home and reducing deaths in hospital. However, achieving this is heavily dependent on carers' contributions.<sup>3 4</sup> Reliance on carers is likely to increase in high-income countries in future,<sup>5</sup> particularly with predicted increases in deaths<sup>6</sup> and years of dependency in later life.<sup>7</sup> Further, during the COVID-19 pandemic in England and Wales, the number of deaths in private homes has increased, while those from leading causes of death in inpatient healthcare have decreased,

indicating how carers may be required to take on added home care when healthcare systems are under strain.<sup>8</sup>

End-of-life caregiving impacts on carers' own psychological and physical health,<sup>9</sup> with carers having worse health than the general population,<sup>10-13</sup> non-caregiving controls,<sup>14 15</sup> carers of people with non-terminal conditions,<sup>16 17</sup> and more anxiety or depression than patients.<sup>12 18</sup>

A better understanding of the factors associated with carers' health would aid planning of initiatives and interventions to improve their health. For instance, if the main factor is hours of care, respite provision is key; if impact on work has a substantial effect, employment law is important; if carer demographics matter, we must investigate why certain carer groups are vulnerable and target support accordingly.

The literature has consistently found that the patient's disease burden at end-of-life impacts negatively on carers' health.<sup>9 19-24</sup> Hours of care are associated with worse carer psychological health within general caregiving<sup>25</sup> and with worse health in some palliative care studies,<sup>19 26</sup> but others have found no relationship.<sup>15 27</sup> Informal help and social network support have shown positive associations with carer health.<sup>12 20 21 28-30</sup> While formal care has shown little positive impact on carer health, we have lacked good quality intervention research.<sup>31 32</sup>

Carers' additional commitments show mixed results. Employment has been linked to more depression,<sup>9</sup> but also to better quality of life<sup>9</sup> and better physical health.<sup>28 33</sup> Having additional care responsibilities may be associated with worse distress.<sup>34</sup> Life impact may also matter: general lifestyle adjustments from caregiving,<sup>34</sup> having to go on leave during employment,<sup>22</sup> and experiencing financial burden or financial strain during caregiving<sup>12 30</sup> have been related to worse psychological health and quality of life, although Tang *et al.*<sup>21</sup> found no relationship with financial burden. Having their sleep affected may be linked to worse anxiety and general health for carers,<sup>33</sup> but the causal direction may be unclear, particularly where anxiety is concerned.

Spouses may suffer greater health impact than other carers,<sup>12 19-21 26 28</sup> although results regarding other relationships are mixed.<sup>9</sup> Female carers have mainly been found to have worse health than male carers<sup>9 27 28 34</sup> but not always.<sup>22</sup> Younger carers mainly suffer greater psychological impacts,<sup>9</sup> while older carers have worse physical health.<sup>26 28</sup> Generally, carers with lower education report worse health<sup>9 28</sup> and those in a better financial situation report better health<sup>20 26 28</sup> than their counterparts.

While some patterns are evident from the literature, overall results are inconclusive. Most studies have involved relatively small samples ( $n < 200$ )<sup>12 13 15 20 21 24 26 28 30 34</sup> and/or samples recruited from palliative/specialist care settings that may not be representative of end-of-life caregiving in general.<sup>12 13 15 19 22 23 26-28 30 33 34</sup> None have so far considered all the variables identified previously within one study.

This paper seeks to improve on previous research by investigating factors associated with carer health

in a large, population-based sample of carers and by considering variables potentially related to carer health together in one study, which would be an important step to establish the main variables in a situation where many variables may be inter-related. For instance, a population-based study showed that those providing most care often had a profile of being female, a spouse or partner, older, retired or unemployed, with lower education and income.<sup>35</sup> However, by considering a more comprehensive set of variables than has previously been tested within multivariate analyses, the study should help control for inter-relationships and identify key, potential predictors of carer health.

We test a preliminary model for factors associated with carer health, incorporating observable variables identified through previous research (figure 1). The model presumes that patients' disease burden (functional decline and symptoms) determines the total hours of care they require to be comfortably looked after,<sup>36</sup> thus affecting caregiving hours or 'objective burden'.<sup>37</sup> Provision of other informal and formal help may mitigate this burden.<sup>12 20 21 28-30 36</sup> We hypothesise that patient disease burden<sup>9 19-24</sup> and caregiving hours<sup>19 25 26</sup> impact negatively on carer health, whereas other informal or formal help has a positive impact.<sup>12 20 21 28-30 36</sup> Additionally, we provisionally assume that additional carer commitments (hours of work, volunteering and other caregiving)<sup>9 34</sup> add pressure and have a negative impact on carer health. Caregiving may have further life impact on carers by increasing financial burden or strain,<sup>12 30</sup> for example, through loss of employment, loss of income and increased expenditure, or by limiting carers' hours of sleep<sup>33</sup> and relaxation, all of which may have a negative impact on carer health. Relationships are likely to matter: the impending loss of a spouse may have greater impact than that of a parent or distant relative.<sup>12 19-21 26 28</sup> Finally, carers' gender,<sup>9 27 28 34</sup> age<sup>9 26 28</sup> and socioeconomic status (SES)<sup>9 20 26 28</sup> are expected to relate to carer health.

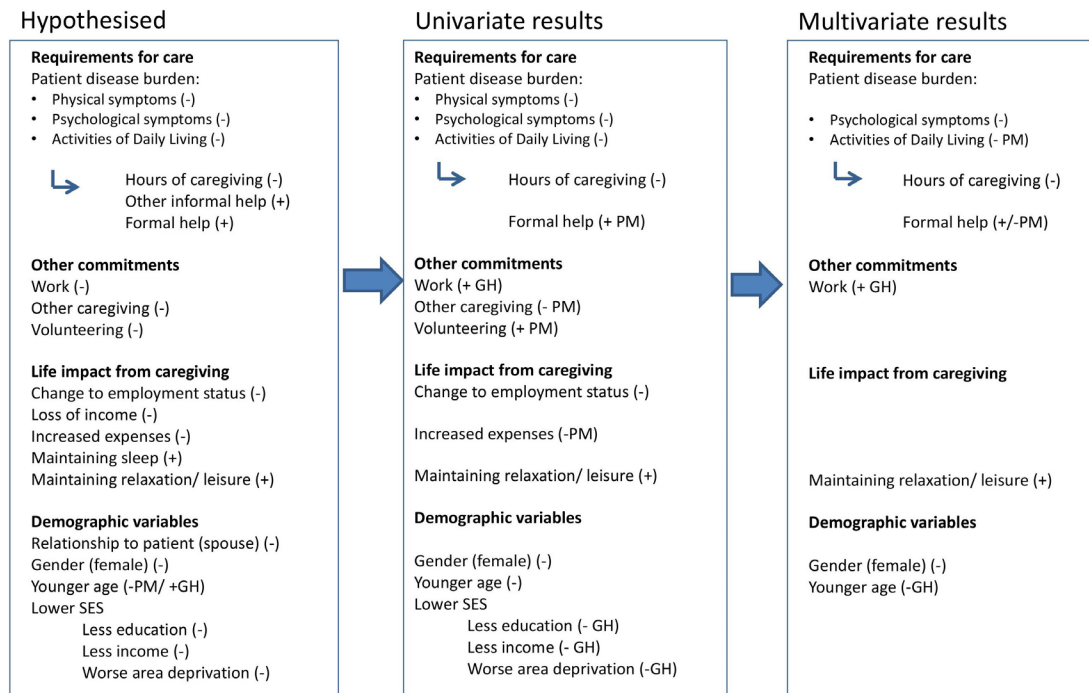
This paper forms part of a larger study.<sup>10 38</sup> The aims were to establish (1) the impact of caregiving on carers' psychological morbidity and general health and (2) the main observable variables that may influence this relationship. The investigation of factors associated with carer health is the focus for this paper, guided by the variables hypothesised to be relevant in figure 1.

## METHODS

We conducted a nationwide, cross-sectional post-bereavement census survey of family carers of people who died from cancer. Methods have been described elsewhere<sup>38</sup> and a summary is presented here.

### Patient and public involvement

Survey contents and procedures were designed in collaboration with lay carers and recently bereaved carers. This included discussing content and formatting of the survey with a lay end-of-life research advisory group, testing a



**Figure 1** Predictors of carer psychological morbidity and general health. +, related to improved health, -, related to worse health, GH, general health only; PM, psychological morbidity only; SES, socioeconomic status.

draft survey with n=5 carers using cognitive debriefing-interviews, and then conducting a pilot survey of n=19 carers followed by carer feedback.

### Sample and recruitment

All those who registered an adult ( $\geq 18$  years) cancer death in England 1–16 May 2015 were identified by the Office for National Statistics (ONS) from death certificates. Exclusion criteria were: death occurred elsewhere than home, hospice, hospital or care home; death was reported to the coroner; the person registering the death was not a relative; the address of relative was missing; or address, sex, or age of deceased was missing.

The ONS sent out survey packs 4 months post-bereavement and two reminders at 1-month intervals, selected as the optimum time frame to allow appropriate distance to the death, yet ensure good accuracy of recall. If recipients felt they had not provided substantial support to the deceased, they were invited to pass it onto a more appropriate respondent.<sup>38</sup> Return of the questionnaire to the research team was taken to indicate informed consent.

As this was a census rather than a sample of the population, we did not do a power calculation for the survey. However, we aimed for a sample of 2000 to allow 95% CIs of carer variables to have a precision of at least  $\pm 2\%$  and to be large enough to undertake multivariable analysis to model potential predictors. According to  $>40\%$  response rates for previous national UK bereavement surveys,<sup>39</sup> this could be achieved by approaching a census sample of n=5000, corresponding to the number of expected deaths over 2 weeks. Although we did not reach the 38%

response rate required to achieve n=2000, we still gained a large enough sample for analysis with some precision.

### Data collected

Survey response data were linked by ONS to data for the whole sampling frame on patient cause of death and demographic data.<sup>38</sup> Survey data covered both psychological and general health and encompassed the variables presented in the Background section as potentially being associated with health.

### Carers' psychological and general health during end-of-life caregiving

Psychological morbidity was measured using General Health Questionnaire (GHQ)-12.<sup>40</sup> Likert scoring of 0-1-2-3 was used for the GHQ-12 4-point scales for bivariate and multivariate analyses as recommended,<sup>41</sup> yielding a composite score of 0–36, with higher scores indicating worse psychological morbidity. General health was measured through the EuroQoL EQ-Visual Analogue Scale (EQ-VAS),<sup>42 43</sup> a single-item scale rated from 0 to 100, where a higher score indicates better health. For GHQ-12, participants were asked to rate how they felt in the decedent's last few weeks of life. For EQ-VAS, participants were asked how they felt on a typical day in the last 3 months of the decedent's life. Different time frames had to be used due to licensing constraints and were discussed with and approved by licence providers. These measures were chosen because they were relatively short, thus limiting response burden in a comprehensive survey while still being recognised, valid measures; because they represented fairly generic measures of overall mental

and general health, rather than being linked to specific components such as anxiety or pain, respectively; and because they permitted comparison with population data on mental and general health from the Health Survey for England. The latter was central to a previous analysis of the survey reported elsewhere.<sup>10</sup>

### Patient disease burden

Main components of the patient's disease burden are their level of physical and mental symptoms and their physical functioning. Symptom burden was assessed by seven items covering the main symptoms experienced in palliative care (pain, nausea/vomiting, constipation, diarrhoea, breathlessness, anxiety, depression, using the question format 'Was your relative affected by any of the following symptoms during their last month of life—pain?'). Physical functioning was assessed through six items covering main activities of daily living (ADLs) (eating, dressing, walking, washing, assistance with toileting, getting up at night, using the question format 'How much help did your relative need with the following activities during their last month of life—eating?'). Responses were on a 4-point Likert scale (0='not at all' to 3='very much'). Following factor analysis, sum scores were taken for physical symptoms (0–12 score), psychological symptoms (0–6 score) and ADL (0–18 score).

### Caregiving for patient

To measure the hours of care that carers provided or objective burden,<sup>37</sup> they were asked how much time (hours:minutes) they spent on each caregiving activity in a typical week in the last 3 months of the decedent's life (see Rowland *et al.*<sup>38</sup> for further details). To measure informal help and formal help received, carers were asked whether they received help (yes/no) from family or friends or from services in those last 3 months. Services encompassed the range of potential support services available to carers and were grouped into general practice (general practitioner and practice nurse); district nurse; other nurse (Macmillan/cancer specialist, Marie Curie or 'other' nurse); social care (social worker, social care staff); self-sought formal help (counsellor, religious leader, cancer support group or telephone helpline); and other support.

### Other commitments

To represent main commitments that may occupy carers' time other than caregiving, carers were asked to report how much time (hours:minutes) they spent on paid employment/looking for work; looking after someone other than the deceased; and volunteer work in a typical week in the decedent's last 3 months.

### Life impact from caregiving

Main life impacts on from caregiving are likely to relate to employment, finances and rest. Carers were asked about changes to employment as a result of caregiving, categorised as change to employment (reducing work hours, quitting job, taking early retirement or stop looking for

work), or no change. Questions also covered income before and after the patient's illness and caregiving expenditure in the decedent's last 3 months. Finally, carers reported hours:minutes spent on sleeping and relaxation in a typical week in the decedent's last 3 months.

### Demographic variables

To cover main demographic and socioeconomic variables, the survey measured carers' gender, age and education level, and their relationship to the decedent. The ONS provided the Index of Multiple Deprivation for their area of residence.

### Statistical methods and analyses

Continuous variables were assessed for normal distribution, skew and kurtosis. Log transformations were conducted on hours, costs and income variables, and square root transformation on EQ-VAS.

Bivariate analysis was undertaken to investigate relationships between hypothesised variables and carer psychological morbidity and general health, using t-tests and analysis of variance to compare differences between two or more groups, respectively, and Pearson's correlations to investigate relationships between continuous variables. To compute CIs for Pearson's correlations, the bootstrap method was used (1000 bootstrap samples). An alpha level of 5% and two-tailed tests were used in all analyses.

Multivariate analysis was undertaken using ordinary least square regression models. Variables that had substantial levels of missing values (those with less than 500 (33%) of a total 1504 cases) were excluded from the candidate list (figure 1) to avoid overfitting the models. Excluded variables were loss of household income, own income, household income and help from other sources. No imputation or other statistical correction was made of missing data, which ranged from <1% to 44%.

GHQ-12 psychological morbidity and EQ-VAS general health were modelled separately using a backward selection approach: for each outcome, we first fitted a complete model with all the candidate variables. The least significant variable was dropped, so long as it was not significant at  $p < 0.01$ , and this was repeated until the  $p$  value of all remaining variables exceeded 0.01. Casewise deletion was used, meaning that only participants with complete data across each variable were included in each statistical test or model.

The residuals of the complete models were normally distributed. There was no evidence of multicollinearity. The models accounted for a limited amount of variability as shown by heteroscedasticity of the residuals (White test), cases identified with extreme influence (Cooks D) and  $r^2$  of 0.12 (EQ-VAS) and 0.23 (GHQ-12).

SPSS V.23<sup>44</sup> was used for the bivariate and Stata V.14<sup>45</sup> was used for regression analysis.

## RESULTS

Response rate was 1504 (28.5%) of 5271. Compared with the total sample approached, participants were more



likely to be from less deprived areas and to have registered a death at home.<sup>38</sup> The mean age of their decedents was 74.4 (SD 12.4); 53.3% were male; and 35.9% died at home, 29.8% in hospital, 19.7% in hospice and 14.6% in a care home. Main primary causes of death were lung (20.1%), colorectal (10.1%), prostate (7.9%) and breast (7.3%) cancers.<sup>38</sup> The mean time between

the patient's death and completion of the survey was 160.2 days (SD 25.2).

**Factors associated with carer outcomes: bivariate analyses**  
 Tables 1 and 2 and figure 1 show the relationships between hypothesised variables and carer outcomes from this analysis.

**Table 1** Relationship between requirements for care and psychological morbidity (GHQ-12) or general health (EQ-VAS)

Predictor variable	Total n	Predictor variable summary statistic for available sample	GHQ-12				EQ-VAS			
			n	Correlation coefficient*	95% CI	P value	n	Correlation coefficient†	95% CI	P value
<b>Patient disease burden</b>		<b>Mean (SD)</b>								
Physical symptom score	1461	5.8 (2.8)	1417	r=0.25	0.19 to 0.30	0.00	1253	r=-0.17	-0.24 to -0.12	0.00
Psychological symptom score	1322	3.2 (1.9)	1285	r=0.34	0.29 to 0.39	0.00	1139	r=-0.29	-0.34 to -0.24	0.00
Activities of daily living scale (transformed)	1469	16.4 (1.0)	1431	r=0.23	0.17 to 0.27	0.00	1263	r=-0.14	-0.20 to -0.08	0.00
<b>Hours of caregiving‡</b>		<b>Median (IQR)</b>								
Preparing food/drink	1247	10:00 (04:45–14:30)	1192	r=0.14	0.08 to 0.21	0.00	1000	r=-0.09	-0.16 to -0.03	0.00
Cleaning	1252	07:00 (03:00–14:00)	1224	r=0.16	0.11 to 0.21	0.00	1084	r=-0.12	-0.19 to -0.06	0.00
'Odd' jobs	1138	03:00 (01:30–06:00)	1115	r=-0.01	-0.06 to 0.05	0.83	982	r=0.04	-0.02 to 0.10	0.20
Shopping	1274	03:00 (02:00–06:00)	1247	r=0.13	0.06 to 0.19	0.00	1108	r=-0.14	-0.20 to -0.08	0.00
Administration	1243	02:00 (01:00–04:00)	1219	r=0.12	0.06 to 0.18	0.00	1081	r=-0.12	-0.19 to -0.06	0.00
Travelling outside house	1162	04:00 (02:00–08:00)	1139	r=0.06	0.00 to 0.12	0.04	1007	r=-0.05	-0.12 to 0.01	0.08
Personal care	1187	07:00 (03:00–14:00)	1161	r=0.18	0.12 to 0.24	0.00	1028	r=-0.13	-0.20 to -0.06	0.00
Organising healthcare	1217	03:00 (02:00–07:00)	1192	r=0.12	0.05 to 0.18	0.00	1061	r=-0.12	-0.18 to -0.06	0.00
Helping with symptoms	1216	05:00 (02:00–10:00)	1189	r=0.16	0.11 to 0.23	0.00	1055	r=-0.15	-0.21 to -0.07	0.00
Social/emotional support	1273	20:00 (08:00–40:00)	1245	r=0.18	0.13 to 0.23	0.00	1109	r=-0.15	-0.21 to -0.09	0.00
Other	330	06:00 (02:30–14:00)	321	r=0.16	0.05 to 0.26	0.01	289	r=-0.19	-0.29 to -0.08	0.00
Total hours spent caring	1365	69:30 (28:37–115:15)	1335	r=0.22	0.17 to 0.27	0.00	1187	r=-0.18	-0.24 to -0.12	0.00
<b>Help received (Y)</b>	<b>n (%)</b>	<b>n</b>	<b>Mean score by group (SD)</b>	<b>Mean difference (SD)</b>	<b>P value</b>	<b>n</b>	<b>Mean score by group (SD)</b>	<b>Mean difference (SD)</b>	<b>P value</b>	
Other informal help	1409 Y: 904 (64)	1374	Y: 19.37 (6.65) N: 19.19 (6.89)	0.18 (0.38)	0.632	1350	Y: 95.65 (1.99) N: 95.75 (2.04)	-0.10 (0.11)	0.372	
GP	1309 Y: 1051 (80)	1280	Y: 19.20 (6.64) N: 20.07 (7.07)	0.87 (0.47)	0.066	1255	Y: 95.70 (1.98) N: 95.63 (2.08)	-0.06 (0.14)	0.659	
District nurses	1189 Y: 917 (77)	1163	Y: 19.42 (6.77) N: 19.94 (7.16)	0.51 (0.48)	0.286	1137	Y: 95.68 (1.99) N: 95.71 (2.01)	0.04 (0.14)	0.760	
Other nurses	1229 Y: 956 (78)	1201	Y: 19.62 (6.73) N: 19.72 (6.86)	0.10 (0.47)	0.833	1176	Y: 95.69 (1.98) N: 95.53 (2.07)	-0.16 (0.14)	0.247	
Social care	894 Y: 418 (47)	878	Y: 19.05 (6.79) N: 20.33 (6.97)	1.28 (0.47)	0.006	867	Y: 95.66 (1.93) N: 95.68 (2.04)	0.02 (0.14)	0.899	
Self-sought help§	971 Y: 577 (59)	951	Y: 19.61 (6.95) N: 19.89 (6.78)	0.28 (0.45)	0.538	936	Y: 95.59 (1.94) N: 95.68 (2.06)	0.09 (0.13)	0.511	
Other	193 Y: 134 (69)	192	Y: 19.80 (6.51) N: 19.03 (6.94)	-0.76 (1.04)	0.465	190	Y: 95.69 (1.87) N: 96.00 (1.99)	0.31 (0.30)	0.306	

All expense values are reported in £British Pounds, all time variables in hours:minutes.

\*A positive correlation indicates worse psychological morbidity.

†A negative correlation indicates worse general health.

‡Hours per week.

§Counselling, support group, religious leader, telephone helpline.

EQ-VAS, EuroQoL EQ-Visual Analogue Scale; GHQ, General Health Questionnaire; GP, general practitioner; N, no; Y, yes.

Patients' disease burden (physical symptoms, psychological symptoms and problems with ADL), total caregiving hours and hours on individual care tasks were associated with worse carer psychological morbidity (GHQ-12) and worse general health (EQ-VAS), except for odd jobs (no effect) and travelling with the patient (worse for psychological morbidity only). Inputs from other informal carers and formal services were unrelated to carer outcomes, except social care contact, which was associated with reduced psychological morbidity.

Other caregiving commitments were related to worse psychological morbidity but not to general health. More hours at work were associated with better general health (but not psychological health), and more hours of volunteering was associated with reduced psychological morbidity (but not general health).

Changes in employment were associated with worse psychological morbidity and worse general health. Total caregiving expenses were associated with worse psychological morbidity, but one-off expenses and loss of income showed no relationship. Hours of relaxation, but not sleep, were associated with reduced psychological morbidity and better general health. Relationship to the patient was not related to health outcomes.

Both psychological morbidity and general health were worse among women than men and worse among younger carers. Higher education, residence in less deprived areas and higher income at the time of diagnoses were associated with better general health.

#### Factors associated with carer outcomes: multivariate analyses

Tables 3 and 4 show the final models. Carers' psychological morbidity (GHQ-12) was worse when patients' psychological symptoms were worse, their need for help with ADL greater, total hours of caregiving higher, carers had used self-sought formal help, or the carer was female. Conversely, carers' psychological morbidity was reduced when there was general practitioner (GP) and social care input, and hours of relaxation were higher. This model explained 23% of variance in psychological morbidity. The patient's psychological symptoms had the greatest effect on psychological morbidity (8% of variability explained), followed by gender (4%), GP input (3%), relaxation (2%), patient's need for help with ADL (2%), hours of care (2%), self-sought formal help (1%), social care (1%) and hours of relaxation (<1%). The model included n=388 respondents with no missing data.

Carers' general health (EQ-VAS) was worse if the patient's psychological symptoms were worse, total hours of caregiving higher and the carer female. General health was better if the carer was older and their hours of employment and relaxation higher. This model only accounted for 12% of the variance. The patient's psychological symptoms had the greatest effect on general health (4% of variability explained), followed by hours of relaxation (2%), work hours (1%), age (1%), hours of caregiving (1%) and gender (<1%). This model included n=771.

## DISCUSSION

Our findings show that worse carer psychological morbidity is associated with increased patient psychological symptoms, need for help with ADLs and caregiving hours. It is plausible that patients' mental state as well as their deterioration towards death will have a combined impact on carers psychologically, in addition to the sheer number of hours of care required. Female carers additionally appeared vulnerable to worse psychological health. Hours of relaxation related to better psychological health, indicating the importance of an ability to have a break. Those with general practice and social care input fared better, but carers who self-sought formal help fared worse, possibly because carers seek such help around crisis points. Palliative care input (indicated by 'other nurses', table 1) was unrelated to psychological health, but the relationship here may be complex, as palliative care recipients may both have greater need and receive better quality of care. Regarding general health, patients' psychological symptoms and the hours of care were again associated with worse carer health, and hours of relaxation and work with better health, and women had worse health than men. Older carers reported better general health than younger carers.

Our results largely confirm findings from previous research, but tell us more about the relative importance of variables. The importance of maintaining other activities and relaxation and the role of primary and social care are new. We found that older carers reported better general health than younger carers, contrasting with some earlier studies.<sup>26 28</sup> While more distress has been reported in spouses and close relatives compared with more distant relatives in the past,<sup>12 19 21 26 28</sup> we found no such effect. However, it is possible that this may become more evident in bereavement, rather than during caregiving. Also, our study combined and controlled for a more comprehensive set of variables than in previous research, which may account for some differences in findings. The interrelationships between the variables, including any mediators, should ideally next be explored in greater depth using longitudinal data and path analysis.

In relation to our model, the findings from the bivariate analysis largely confirmed the hypothesised relationships. However, contrary to our hypotheses, work and volunteering were related to better, rather than worse, general and psychological health, respectively. Further, other informal help, loss of income, sleep and being a spouse showed no relationship with health. The multivariate analysis indicates that only a few variables remained significant once confounders are controlled for, but these spanned all the hypothesised broader categories of patient disease burden (psychological symptoms and ADL), care input (carer's hours of caregiving and formal generalist help), other commitments (work), life impact (maintaining relaxation/leisure) and demographic variables, indicating a need to maintain a broad focus when considering factors associated with carer health.

This is the first study to be conducted with a large population-based sample of end-of-life carers to test the full range of observable factors related to carer health

**Table 2** Relationship between other commitments/socioeconomic factors and psychological morbidity (GHQ-12) or general health (EQ-VAS)

Predictor variable	GHQ-12			EQ-VAS					
	Total n	Predictor variable statistic for available sample	n	Correlation coefficient*	95% CI	P value	Correlation coefficient†	95% CI	P value
<b>Other commitments</b>									
Hours at work‡	1026	Median (IQR) 7 (0–35)	1007	r=–0.02	–0.08 to 0.04	0.55	r=0.12	0.06 to 0.19	0.00
Hours of other caring‡	926	0 (0–10)	910	r=0.07	0.01 to 0.13	0.03	r=–0.06	–0.12 to 0.02	0.11
Hours of volunteering‡	843	0 (0–0)	829	r=–0.14	–0.21 to –0.07	0.00	r=0.07	–0.01 to 0.14	0.07
<b>Life impact from caring</b>									
Loss of own income	438	0 (0–0)	432	r=0.01	–0.05 to 0.10	0.78	r=–0.02	–0.10 to 0.08	0.65
Loss of household income	375	0 (0–850)	372	r=0.08	–0.01 to 0.15	0.14	r=–0.08	–0.15 to 0.03	0.19
Total care expenses in 3 months before death	1090	370 (150–919)	1072	r=0.09	0.04 to 0.16	0.00	r=–0.01	–0.07 to 0.05	0.69
Total cost of any extra one-off expenses	240	2000 (756.25–5875)	236	r=0.02	–0.10 to 0.16	0.77	r=0.04	–0.08 to 0.16	0.52
Hours of sleep‡	1237	42 (35–49)	1214	r=–0.03	–0.09 to 0.03	0.29	r=0.06	–0.02 to 0.14	0.06
Hours of relaxation‡	1079	5 (0–14)	1058	r=–0.20	–0.26 to –0.14	0.00	r=0.21	0.14 to 0.28	0.00
<b>Change in employment status (Y)§</b>									
Change in employment status (Y)§	1418	Y: 638 (45)	1377	Y: 20.38 (6.64) N: 18.42 (6.77)	–1.96 (0.36)	0.001	Y: 95.51 (1.93) N: 95.86 (2.03)	0.35 (1.10)	0.001
<b>Demographics of the respondent</b>									
Relationship to patient	1476	n (%)	1430	Mean score by group (SD)	Mean difference (SD)	P value	Mean score by group (SD)	Mean difference (SD)	P value
Spouse		669 (45)		19.49 (6.93)		0.139	95.59 (2.03)		0.074
Child		650 (44)		19.47 (6.60)			95.70 (1.92)		
Other		157 (11)		18.32 (6.86)			96.01 (2.19)		
Sex (female)	1483	Y: 966 (65)	1446	Y: 20.22 (6.76) N: 17.70 (6.51)	–2.52 (0.37)	0.001	Y: 95.47 (2.01) N: 96.11 (1.93)	0.64 (0.11)	0.001
Education (≥college)	1389	Y: 752 (64)	1359	Y: 19.37 (6.76) N: 19.50 (6.73)	0.13 (0.37)	0.714	Y: 95.85 (1.95) N: 95.48 (2.04)	–0.38 (0.11)	0.001
Index of Multiple Deprivation (quintiles)	1493		1446			0.034			0.002
<b>Most deprived</b>									
1		155 (10.3)		20.15 (7.06)			95.29 (2.20)		
2		216 (14.4)		19.89 (6.94)			95.44 (2.02)		
3		320 (21.3)		19.90 (7.24)			95.58 (2.02)		
4		367 (24.4)		18.99 (6.63)			95.79 (1.90)		
Least deprived 5		435 (28.9)		18.69 (6.35)			95.95 (1.96)		

Continued

Table 2 Continued

Predictor variable	Total n	Predictor variable summary statistic for available sample			GHQ-12			EQ-VAS				
		n	Mean (SD)	Median (IQR)	n	Correlation coefficient*	95% CI	P value	n	Correlation coefficient†	95% CI	P value
Age	1480	1444	60.4 (12.3)		1444	r=-0.16	(-0.21 to -0.10)	0.00	1278	r=0.06	(0.10, 0.10)	0.04
Own income at diagnosis	447	441	1400 (900-2200)		441	r=-0.03	(-0.14, 0.07)	0.53	375	r=0.13	(-0.01, 0.26)	0.01
Household income at diagnosis	396	392	2586 (1659.75-4000)		392	r=-0.04	(-0.14, 0.06)	0.47	330	r=0.08	(-0.02, 0.20)	0.15

All expense values are reported in £GBP, all time variables in hours:minutes.

\*A positive correlation indicates worse psychological morbidity.

†A negative correlation indicates worse general health.

‡Hours per week.

§Reduced hours, quit job, stopped looking for work, retired, or made other change that involved moving to new employment category.

EQ-VAS, EuroQol EQ-Visual Analogue Scale; GHQ, General Health Questionnaire; N, no; Y, yes.

identified in past research. In contrast, previous research has involved small samples<sup>12 13 15 20 21 24 26 28 30 34</sup> and/or carers of patients recruited from palliative or specialist care<sup>12 13 15 19 22 23 26-28 30 33 34</sup> who are unlikely to be representative of end-of-life caregiving. Our population related to deaths from cancer, whose end-of-life trajectory may be more progressive and defined than for other conditions.<sup>46</sup> However, this population is likely to have a well-recognised end-of-life period and need for carer input, which were the topic of our study.

We have little information on non-responding carers for this dataset, only in the form of limited information on the patient they cared for. Compared with the total sample approached, respondents were more likely to have supported someone mostly at home rather than in inpatient settings and were from less deprived areas.<sup>38</sup> Although differences were relatively minor, this may mean respondents provided more caregiving hours but also had higher SES. Findings may therefore be less representative of carers who provided fewer caregiving hours, experienced more inpatient care and had lower SES. While survey findings can be adjusted for non-response by applying weights to under-represented groups, in this case, those whose family member spent more time in the hospital and from less deprived areas, this does make strong assumptions about the similarities of scores between respondents and non-respondents, which may or may not be valid. Therefore, without more data on non-respondents, which we did not have, we feel it would not be prudent to follow this process. However, issues of representativeness of scores are more likely to affect the estimated prevalence and means of variables considered, while the relationships between variables (ie, potential predictors and outcomes) are likely to be more consistent and robust across groups.

The time between registering the death and our survey was relatively short to enhance recall. However, we acknowledge that retrospective data may have their limitations. To facilitate accuracy of recall, we built in checks (eg, carers were asked to summarise, check and calibrate their hour estimates against the total hours in a week) and ensured concepts were linked to more tangible components (eg, GHQ-12 seeks to measure tangible indicators of distress rather than more diffuse emotions; EQ-5D VAS was completed after participants reviewed the specified components constituting quality of life in the EQ-5D). Therefore, overall patterns observed should be sound, although some predictors may have been given greater or lesser weight due to influences of recall. The fact that this study largely replicates findings from past research lends further credence to results. It should furthermore be recognised that the challenges of identifying patients and defining the final months of life prospectively, combined with potential distress from data collection while the patient is dying, mean a retrospective approach may be the only feasible way of generating a large, population dataset of caregiving in the final months of life.<sup>10</sup>



**Table 3** Psychological morbidity (GHQ-12) multivariable analysis

	<b>B coefficient (95% CI)</b>	<b>SE B</b>	<b>Effect size partial Eta<sup>2</sup></b>	<b>T</b>	<b>P value</b>
Patient's psychological symptoms	1.04 (0.67 to 1.39)	0.18	0.08	5.83	<0.001
Patient's activities of daily living	0.16 (0.03 to 0.28)	0.06	0.02	2.49	0.013
Total hours of caregiving	0.69 (0.16 to 1.22)	0.27	0.02	2.54	0.011
GP supportive input	-2.23 (-3.60 to -0.87)	0.69	0.03	-3.22	0.001
Social care supportive input	-1.29 (-2.57 to -0.01)	0.65	0.01	-1.98	0.049
Self-sought help	1.36 (0.13 to 2.60)	0.63	0.01	2.18	0.030
Sex	2.57 (1.31 to 3.83)	0.64	0.04	4.01	<0.001
Hours volunteering	-0.14 (-0.31 to 0.02)	0.09	<0.01	-1.69	0.091
Hours of relaxation	-0.19 (-0.32 to -0.06)	0.07	0.02	-2.87	0.004
Constant	7.70 (0.87 to 14.53)	3.47	-	2.22	0.027

$F_{9,378}=13.93$ ,  $p<0.001$ ;  $R^2=0.249$ ,  $AdjR^2=0.231$ ,  $n=388$ . Partial Eta<sup>2</sup> calculated using the estat command. High GHQ-12 score indicates worse psychological morbidity; positive B coefficient indicates worse morbidity. GHQ, General Health Questionnaire; GP, general practitioner.

For example, Nielsen *et al*<sup>17</sup> were able to gain data from a large prospective palliative population sample, but illustrate the challenges of conducting prospective research into the final months of life. The study relied on health-related prospective national datasets with timely access for researchers, which are unavailable in many other nations. Identification of participants relied on a physician's definition of someone as being incurably ill and entitled to drug reimbursement. This yielded a sample predominantly consisting of carers of patients with cancer, and largely missed people dying from other conditions. Furthermore, half the sample had a longer patient survival than 3 months, in part because the criteria identified a broader palliative population, but also because carers of those closer to death were significantly less likely to respond. In the absence of accurate prognosis, longitudinal studies prebereavement can enable us to gain data closer to death, but this increases the carer response burden and carers are still more likely to withdraw as death nears. Further, this still depends on national datasets for timely access to palliative patients

in the first place. This means we often will have to fall back on retrospective data collection based on death data when focusing on the final months of life, or rely on data from carers of patients who are least unwell and whose prognosis can be most easily determined.

Nevertheless, retrospective reports of mental and general health should be treated with caution as they may be affected by carers' current health. It will be important to undertake longitudinal research into prebereavement and post-bereavement reports of mental and physical health during caregiving to better understand how they relate and how retrospective post-bereavement measures can be better calibrated. Furthermore, our study involved cross-sectional measurement of hypothesised variables and outcomes, which limit the conclusions that can be drawn about causal relationships. Again, longitudinal research is required to illuminate these further.

Our results indicate that particular attention should be given to carers' support needs when the patient has a high level of psychological symptoms, being the main factor associated with carers' psychological morbidity

**Table 4** General health (EQ-VAS) multivariable analysis

	<b>B coefficients (95% CI)</b>	<b>SE B</b>	<b>Effect size partial Eta<sup>2</sup></b>	<b>T</b>	<b>P value</b>
Patient's psychological symptoms	-0.21 (-0.28 to -0.14)	0.04	0.04	-5.77	<0.001
Total hours of caregiving	-0.14 (-0.24 to -0.04)	0.05	0.01	-2.86	0.004
Sex	-0.30 (-0.57 to -0.02)	0.14	<0.01	-2.13	0.034
Age	0.02 (0.01 to 0.03)	0.01	0.01	3.16	0.002
Hours of work	0.04 (0.02 to 0.07)	0.01	0.01	3.17	0.002
Hours of relaxation	0.05 (0.02 to 0.08)	0.01	0.02	3.15	<0.001
Constant	6.56 (5.06 to 8.06)	0.77	-	8.57	<0.001

$F_{6,764}=18.91$ ,  $p<0.001$ ;  $R^2=0.129$ ,  $AdjR^2=0.123$ ,  $n=771$ . Partial eta<sup>2</sup> calculated using the estat command. High EQ-VAS score indicates better general health; positive B coefficient indicates better health. EQ-VAS, EuroQoL EQ-Visual Analogue Scale; GP, general practitioner.



and general health. Being able to do something different from caregiving, whether relaxation or work, seems beneficial both to psychological and general health. This is not simply a result of spending fewer hours on caregiving, as caregiving hours and other activities both emerged as being independently associated with carer health. However, permitting yourself to engage in other activities during a family member's last months can be difficult, and it may be that carers who feel able to do so are different from those who do not. Women had worse psychological and general health than men, possibly due to greater willingness to express distress,<sup>48</sup> but gender role expectations and caregiving context may affect women more.<sup>29</sup> Input from primary and social care related to improved psychological health. Arguably, anyone within the last months of life should be eligible for such support, but not everyone may receive it.

Findings indicate that the end-of-life carers in greatest need of support are those looking after patients with psychological symptoms and spending many hours on caregiving with little opportunity for other activities. Female carers warrant particular attention and support. Additionally, good primary and social care provision appears to be important. Further investigation into the cause and effect relationship between some of these variables (eg, other activities and formal care) and more sophisticated modelling techniques to explore potential moderating and modulating effects would further inform appropriate intervention.

The variables in this analysis account for an important, although relatively small, percentage of the variance in carer outcomes. A lot of the remaining variance is likely to be explained by individual variation, for example, in carers' subjective appraisals of their situation and burden.<sup>9</sup> Development of population models of potential predictors of carer health to aid planning, such as that presented here, should therefore not detract from the need to work with individual carers to assess their health and support needs. Initiatives to support carers both at population and individual levels are urgently required. Our reliance on carers' ability to provide home care has been thrown into sharp relief by the current pandemic, where, for instance, England and Wales have seen a shift in deaths from hospital to private homes,<sup>8</sup> and carers have been expected by NHS England to take on more skilled caregiving tasks at home.<sup>49</sup> Our reliance on carers in general is likely to increase in the future,<sup>5</sup> particularly given projected increases in deaths<sup>6</sup> and dependency in later life.<sup>7</sup>

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