Caregiving for older people living with chronic pain: analysis of the English longitudinal study of ageing and health survey for England

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Abstract

Background: Chronic pain is a disabling condition. Many people with chronic pain seek informal support for everyday activities of daily living (ADL). However, there remains uncertainty on the type of people with chronic pain who access this support, what types of support they need and who provides such support. The purpose of this analysis was to answer these uncertainties.

Methods: Data from the Health Survey for England (HSE) and English Longitudinal Study of Ageing (ELSA) were accessed. People who reported chronic pain (moderate or above for minimum of 12 months) were identified. From these cohorts, we determined if individuals self-reported receiving informal care. Data on caregiver profiles and caregiving activities were reported through descriptive statistics. Logistic regression analyses were performed to compare health status outcomes between people with pain who received and who did not receive informal care.

Results: 2178 people with chronic pain from the ELSA cohort and 571 from the HSE cohort were analysed. People who received care were frequently female, older aged with several medical morbidities including musculoskeletal diseases such as arthritis. People with chronic pain received informal care for several diverse tasks. Most frequently these related to instrumental activities of daily living (IADL) such as shopping and housework. They were most frequently provided by partners or their children. Although they reported greater disability and symptoms ($p < 0.001$), people who received care did not report differences in health status, loneliness or wellbeing ($p = 0.27$; $p = 0.46$).

Conclusions: Whilst it may be possible to characterise people living in chronic pain who receive informal care, there is some uncertainty on the impact of informal caregiving on their health and wellbeing. Consideration should now be made on how best to support both care recipients and informal caregivers, to ensure their health and quality of life is promoted whilst living with chronic pain.

Keywords
Persistent pain, support, care, family network, national cohort

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Introduction

Chronic pain is a disabling condition for all ages of people.[1] It has been defined as pain that persists or recurs for more than 3 months.[2] Chronic pain may arise from several sources including musculoskeletal (bone, joint, muscle), or neurological origins, cancer or infection. Many people have more than one body region affected.[3] Globally, chronic pain is a leading cause of years lived with disability in people aged 70 years and over.[4] Low back pain (LBP) is a top 10 leading cause of disability worldwide.[4] Approximately 9.1 million people live with long-term back pain in England.[5] Chronic pain poses a personal cost to the individual and their friends and family and adds a burden onto health and social care services.[6,7] Accordingly, national and international policies on chronic pain management are currently focused on a multimodal approach, increasing self-management skills, reducing opioid use and prioritising non-pharmacological treatments for pain were possible.[8–12]

Chronic pain is a common problem among older people.[13] Whilst conflicting evidence exists related to differences in pain processing and treatment response in older compared to younger people with chronic pain,[14] there has been limited evidence exploring different treatment approaches between age-groups. However, because of medical comorbidities and associated polypharmacy, managing symptoms in older people with pharmacological and non-pharmacological approaches, can be challenging.[15] Furthermore, chronic pain increases falls-risk for older people.[16] Given fall-injuries are a leading cause of death in older adults,[16] this is a particularly important health challenge for an ageing population.

People living with chronic pain, whether younger or older, frequently have difficulties managing symptoms and everyday activities to maintain independence and quality of life.[17] Consequentially, they often access support for tasks such as: washing and dressing, preparing meals, eating, housework or shopping.[18,19] This caregiving may be formal or informal. Formal care is the provision of care by someone who is paid. Informal care is provided without direct financial payment.

There remains uncertainty over the profile of people living with pain who access informal care, and what care provision constitutes for them. Accordingly, the purpose of this study was to determine, in a representative cohort in England:

(1) the profile of people with chronic pain who receive informal care
(2) who provides informal care for people living with chronic pain

(3) how much informal care people with chronic pain receive
(4) which activities do people with chronic pain receive support
(5) whether there is a difference in health status between people with chronic pain who receive informal care compared to those who do not.

Materials and methods

We conducted a comparative prospective cohort study reported using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.[20]

The characteristics and profile of people resident in England, who reported moderate chronic pain or greater, from two published cohorts, were analysed. These cohorts were:

(a) The English Longitudinal Study of Ageing (ELSA). This commenced in 2002 and is an ongoing study of the health, social and economic lives of a cohort of people aged 50 years and older in England.[11] It is a nationally representative household survey that monitors trends in the population's health every 2 years.[21]
(b) The Health Survey for England (HSE). This is an annual survey administered since 1991 to monitor trends in national health and to estimate the prevalence of specific health conditions. This collects data during an interview on sociodemographic characteristics, employment, health conditions and clinical measurements.

English Longitudinal Study of Ageing and HSE data are publicly available and were downloaded from the UK Data Service (https://ukdataservice.ac.uk/). Both cohorts were selected as they provide data on caregiving and care receipt for people with moderate pain or greater and offer different measures of health status to indicate the broader impact of caregiving on health and wellbeing.

Wave 7 (June 2014 to May 2015) ELSA data and the HSE (January 2019 to March 2019) data were identified as the most pertinent and contemporary to offer the required cross-sectional variables on caregiving and pain data to answer our research questions.

Participants

From each dataset, we identified people who self-reported with moderate pain or greater. English

Table 1. Variables selected to answer the four a priori research questions from the ELSA/HSE informal caregiving analysis.

Demographic/characteristics variables
Gender
- Age
- Marital status
- Live alone (one or more people)
- Ethnicity (HSE)
- National statistics socio-economic classification (five-items) (HSE)
- Religion
- Pain severity
- Pain felt yesterday (ELSA)
- Pain VAS score (LBP, hip, knee, foot – ELSA)
- Comorbidities and self-reported health

Caregiving activities – level of support required for activities including:
- Individual providing support for specific activities (i.e. partner, son, daughter, friend)
- Number of informal caregivers
- Time provided for informal caregiving per week by activity and by caregiver
- Whether caregiving needs were met

Clinical status of person with chronic pain measured by:
- CASP-19[13] (ELSA)
- University of California, Los Angeles Loneliness Scale (R-UCLA)[14] (ELSA)
- EQ-5D-3L[17] (HSE)
- General health questionnaire-12[16] (HSE)
- Satisfaction with life scale[15] (HSE)
- Barthel index data[18] (HSE)

ELSA– England Longitudinal Study of Ageing; HSE– Health Survey of England; LBP– Low Back Pain; VAS– Visual Analogue Scale

Longitudinal Study of Ageing categorised this as individuals with self-reported moderate or severe pain; HSE categorised this as a self-report of moderate, severe, or extreme pain. To provide greater certainty that self-reported pain reflected the intended 'chronic pain' population, we compared the responses against the visual analogues scale (VAS) assessment of LBP, hip, knee and foot pain (0–10 point scale). To ensure participants were those who experienced persistent symptoms (12 months minimum), all participants were required to report pain severities of moderate or greater at both the analysed and previous ELSA/HSE data collection interval to be included in our analysis.

To determine whether a participant received or did not receive informal care, we determined care receipt, for each dataset, as a composite of the response to (1) the number of informal caregivers assisting (ELSA/HSE), (2) requirement for assistance responses (ELSA) and (3) whether they received help with activities of daily living (ADLs) such as washing, dressing, eating or instrumented ADLs (IADLs) such as shopping, travelling and managing medicines (HSE). These were considered appropriate as reflective of the wide-range of activities an informal caregiver may offer an individual they support.[17–19]

Variables

To understand the profile of people living with chronic pain who received informal care, we selected variables based on existing studies and theoretical assumptions of what could be explanatory variables to answer the research questions, based on the meta-ethnography by Smith et al.[22] These are summarised in Table 1. In brief, we selected demographic variables, data on caregiving activities, and finally data on clinical presentation for people living with pain receiving or not receiving informal care. This number of prioritised variables was selected to allow the assessment of the research questions posed, without being at the expense of reduced analytical power.[23] Furthermore, variables were prioritised when they reported the same data through similar questions in each dataset, to allowed clearer comparison between the cohorts.

Statistical analysis

Analyses were performed as complete case analyses in each cohort separately. English Longitudinal Study of Ageing longitudinal weights are only available for core sample participants. Applying longitudinal weights to our analysis would have resulted in a reduction in analytical sample size

and therefore reduced statistical power. Consequently, we used the unweighted sample for our analyses.

We performed descriptive analyses on the characteristics of care recipients using means and 95% confidence intervals (CI), medians and inter-quartile ranges (IQR) or frequencies with percentages to answer the research questions: (question 1) description of the profile of people with chronic pain who receive informal care; (question 2) who provides informal care for people living with chronic pain; (question 3) how much informal care do people with chronic pain require; and (question 4) for which activities do people with chronic pain frequently require support. We presented the duration of informal caregiving, by the individual providing the care, using stack bar charts.

To assess whether there is a difference in health status between people with chronic pain who receive informal care compared to those who do not (research question 5), we performed logistic regression analyses for dichotomous data presented with odd ratios (OR) and 95% CI and linear regression analyses presented as mean differences (MD) and 95% CI for continuous data. All p-values generated from the analyses were considered statistically significant if $p < 0.05$.

Analyses were performed using Stata/MP 17.0 for Windows (StataCorp LLC, Texas 77845, USA).

Results

Sample characterises

Figure 1 illustrates the derived and analysed cohorts from the Wave 7 ELSA and HSE 2018 datasets. As this illustrates, from the 9666 respondents in the ELSA cohort, 1045 people with moderate or severe pain received informal care compared to 1133 respondents who did not. From the 10,250 HSE cohort, 1361 participants reported moderate, severe or extreme pain. Of these, 356 received informal care whereas 215 did not.

Wave 7 ELSA

Profile of people with chronic pain receiving informal care. A summary of the characteristics of those who received care for chronic pain is presented in Table 2. This illustrates that people with chronic pain who received informal care were more frequently female (70%), married (69%), lived with one or more people (63%) and were living with moderate rather than severe pain (64% vs. 36%). Common comorbidities presented included osteoarthritis (60%), depression (17%),

asthma (16%) and osteoporosis (15%). Whilst people receiving informal care self-reported help as 'very good' or 'good' (58%), 11% reported this as 'fair' and seven percent as 'poor'. The mean CASP-19[24] and R-UCLA[25] scores indicate people with chronic pain who received informal care reported moderate well-being and loneliness, with mean scores of 36.3 (95% CI: 36.0–36.8) and 4.11 (95% CI: 4.01–4.21), respectively.

Profile of informal care provision. As Table 3 illustrates, care recipients required a variety of support with ADLs and IADLs. The most frequently reported tasks which required assistance were household chores (75%), shopping (63%), dressing (34%) and walking (29%). Least frequently reported included toileting (8%), eating (9%) and support negotiating steps and stairs (9%). The mean number of activities participants required assistance with was 3.3 tasks (95% CI: 3.1–3.4). In total, 63% of participants reported their care needs were met all the time, 9% reported care needs were met 'sometimes' or 'hardly'.

Most frequently, informal caregivers were partners (50%), daughters (25%) or sons (19%). Nonetheless, various individuals were reported as caregivers, including friends (10%) and neighbours (4%). The median number of different caregivers' participants reported having was one (IQR: 1–2), with 26.2% of participants reporting two or more caregivers.

Figure 2 illustrates the time provided for assistance to care recipients per week. The most frequent duration was one to 4 h per week. Partners and daughters most frequently provided the highest duration of support at 100 h or more per week.

Health status of people with chronic pain who receive informal care compared to those who do not. As presented in Table 4, care recipients reported better self-reported health (39.1% vs 45.4%; $p = 0.01$) but no differences were identified for wellbeing when measured with the CASP-19[24] (MD: 0.30; $p = 0.27$) or loneliness measured using the R-UCLA[25] (MD: 0.91; $p = 0.46$) compared to those who do not receive informal care.

Health survey for England

Profile of people with chronic pain receiving informal care. A summary of the characteristics of those who received care for chronic pain from the HSE cohort is presented in Table 5. This illustrates that people with chronic pain who received informal care were more frequently female (65%), aged 70–79 years (44%), married (49%) and were or had been in semi-routine (39%) or managerial and professional occupations (23%). Fifty-
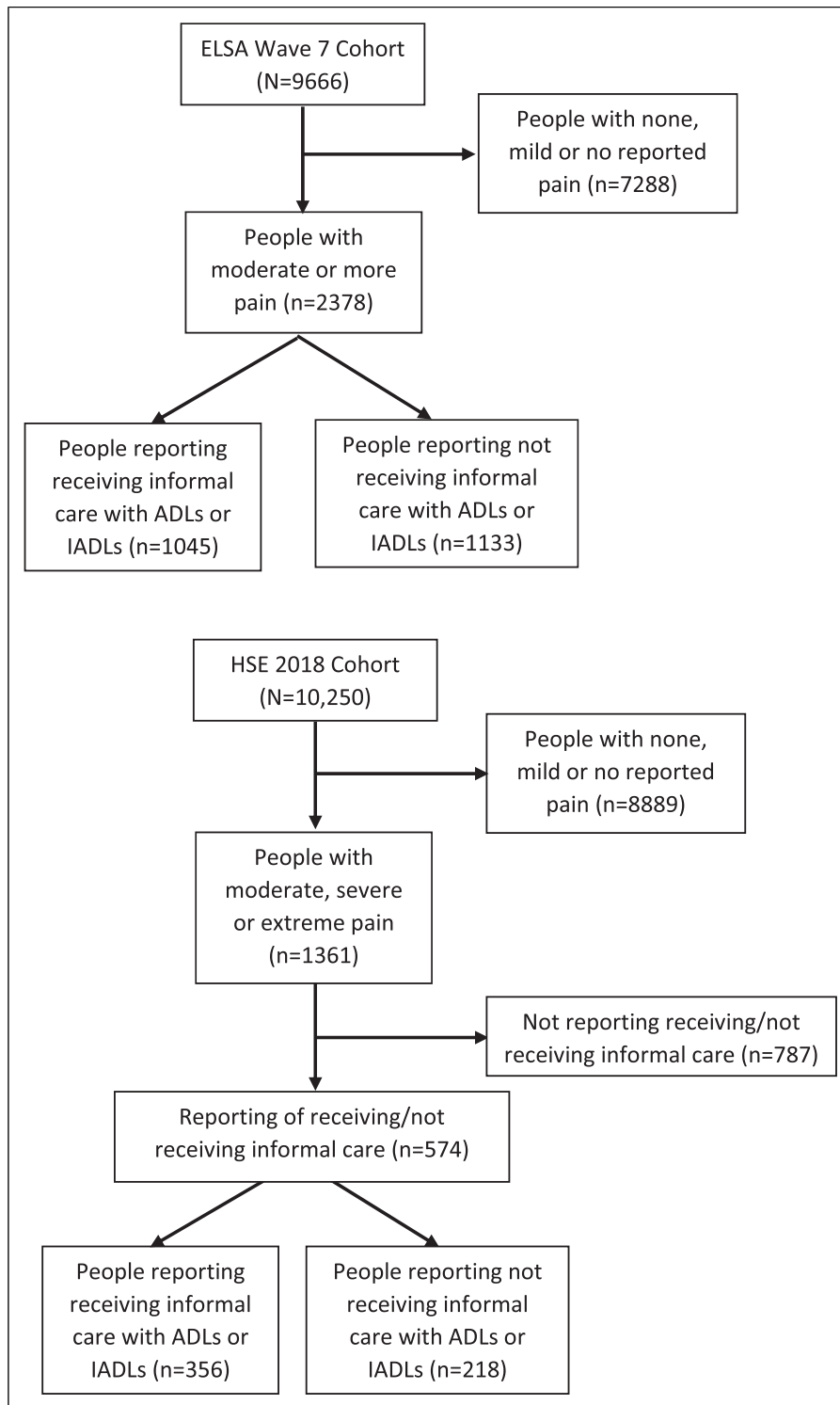
Figure 1. Flow chart illustrating cohort composition from respective datasets.

seven percent of people with chronic pain reported living with someone else. Eighty-three percent of care recipients considered themselves religious, with Christianity being the most frequently reported religion (76%). Most care recipients reported living with moderate rather than severe pain (57% vs. 34%). Common comorbidities presented included musculoskeletal conditions (74%), heart or circulatory conditions (36%) whilst 21% reported

Table 2. Table illustrating the profile of people with moderate to severe chronic pain in the ELSA Wave 7 cohort who receive informal care.

		Receive informal care
N		1045
Gender	Male	314 (30.1)
	Female	731 (69.9)
Mean age (95% CI)		71.0 (70.4–71.6)
Marital status	Married (first only)	573 (54.8)
	Married (second or more)	150 (14.4)
	Divorced and not remarried	144 (13.8)
	Single and never married	130 (12.4)
	Separated but legally married	26 (2.5)
	Civil partners in same-sex marriage	5 (0.5)
	Widowed	17 (1.6)
Lived with one or more person		658 (63.0)
Subjective pain grade	Moderate	669 (64.0)
	Severe	376 (36.0)
Pain score – LBP (*N* = 1281)		6.1 (5.9–6.3)
Pain score – Hip (*N* = 847)		4.7 (4.4–5.0)
Pain score – Knee (*N* = 1207)		6.1 (5.9–6.3)
Pain score – Foot (*N* = 699)		6.0 (5.8–6.3)
Comorbidities (frequency Yes; %)	Anxiety	124 (11.9)
	Depression	172 (16.5)
	OA	625 (59.8)
	RA	140 (13.4)
	Dementia	10 (1.0)
	Parkinson's disease	13 (1.2)
	Cancer	19 (1.8)
	Osteoporosis	160 (15.3)
	Asthma	170 (16.3)
	Diabetes	50 (4.8)
	Stroke	76 (7.3)
	Congestive cardiac failure	11 (1.1)
	Myocardial infarct	7 (0.7)
	Angina	9 (0.9)
	Hypertension	93 (8.9)
Self-reported health	Excellent	187 (17.9)
	Very good	287 (27.5)
	Good	317 (30.3)
	Fair	113 (10.8)
	Poor	68 (6.5)
	Not reported	73 (7.0)
CASP-19 total (mean; SD) (*N* = 1735)		36.3 (36.0–36.8)
CASP-19 (*N* = 1735)	0–29 points	87 (10.8)
	30–57 points	721 (89.2)
UCLA 3-item score (mean; SD) (*N* = 1780)		4.11 (4.01–4.21)
UCLA (*N* = 1780)	3–5 points	675 (81.9)
	6–9 points	149 (18.1)

CI – confidence intervals; LBP – low back pain; *N* – number of participants; OA – osteoarthritis; RA – rheumatoid arthritis; SD – standard deviation; UCLA – University of Los Angeles.

respiratory conditions. Self-reported health was described in people receiving informal care as 'fair' in 42% and 'bad' in 29%, whilst 59% reported this as 'very good' or 'good'. The mean Life Satisfaction Score,[26] General Health Questionnaire score-12[27] and EQ-5D-3L[28] indicated 'medium' life satisfaction, mental health status and HRQoL but the mean Barthel score[29] of 17 points indicated care recipients had high levels of disability.[30]

Table 3. Table illustrating the care provision for individuals with moderate to severe pain in the ELSA Wave 7 cohort who receive informal care.

		Receive informal care
N		1045
Requirement for assistance (frequency Yes; %)	Walking	299 (28.6)
	Stairs and steps	93 (8.9)
	Dressing	354 (33.9)
	Bathing	278 (26.6)
	Eating	93 (8.9)
	In/Out of bed	156 (14.9)
	Toileting	79 (7.6)
	Shopping	662 (63.4)
	Take medications	130 (12.4)
	Household chores	783 (74.9)
	Money and bills	163 (15.6)
Number of activities require assistance (mean; SD)		3.3 (3.1–3.4)
Provider of assistance (frequency; %)	Partner	525 (50.2)
	Son	199 (19.0)
	Daughter	264 (25.3)
	Grandchild	58 (5.6)
	Sister	25 (2.4)
	Brother	14 (1.3)
	Other relative	34 (3.3)
	Friend	102 (9.8)
	Neighbour	37 (3.5)
Number of different caregivers (median; IQR)		1.0 (1.0–2.0)
Number informal caregivers assisting (frequency; %)	0	0 (0)
	1	771 (73.8)
	2	202 (19.3)
	3	56 (5.4)
	4	13 (1.2)
	5	3 (0.3)
Assistance provided meet person's needs (Yes; %)	Meets need all time	660 (63.2)
	Usually meets need	249 (23.8)
	Sometimes	84 (8.0)
	Hardly	7 (0.7)
	Informal care not received	45 (4.3)

IQR - inter-quartile range; *N* – number of participants; SD – standard deviation.

Profile of informal care provision. The receipt of informal care for people living with moderate, severe or extreme pain in the HSE cohort is summarised in Table 6. These participants required a variety of support. Most frequently, reported tasks were navigating steps and stairs (80%), shopping (70%), help with household chores (67%) and walking outdoors (56%). Least frequently reported included toileting (11%), eating (14%) and support taking medications (14%). Most participants reported needing help for two or more activities (83%). Tasks frequently reported as unmet care need tasks included navigating steps and stairs (67%), walking indoors (26%), transferring in and out of bed (24%) and bathing (23%).

The most frequent informal caregivers were partners (25%), daughters (24%) or sons (12%). Outside the family network, friends provided informal caregiving for eight percent of the cohort and neighbours for three percent.

Figure 3 illustrates the time provided for assistance to care recipients per week. For all providers, the most frequent duration was one to 4 hours per week. Partners provided the greatest frequency of 100 h or more support.

Health status of people with chronic pain who received informal care compared to those who do not. As presented in Table 7, care recipients reported poorer life satisfaction (MD: 1.44; $p < 0.001$), more likely to report mental distress using the GHQ-12 (12.8% vs 36.0%; $p < 0.001$), had greater disability measured using the Barthel score (MD: 2.77; $p < 0.001$) and lower HRQoL
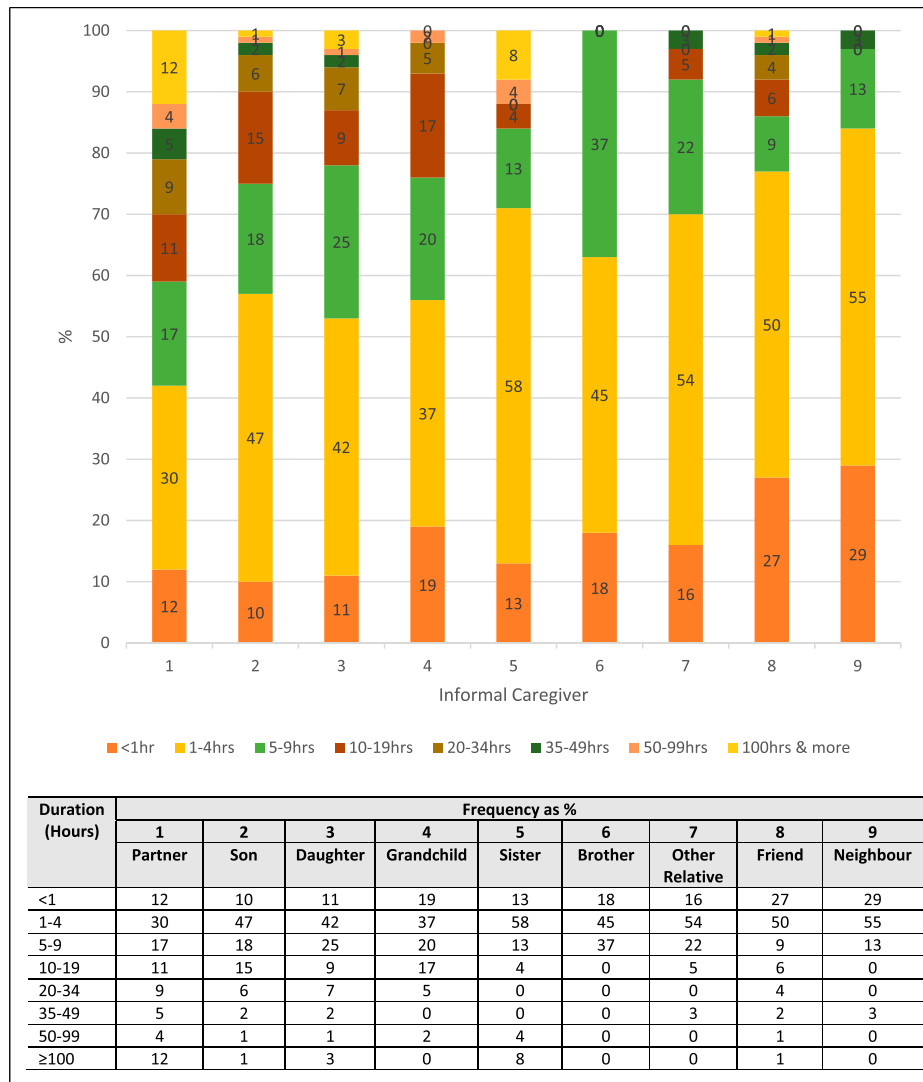
Figure 2. Stack bar chart of hours of informal care provided by caregiver for person with moderate to severe pain reported in the Wave 7 ELSA cohort.

Table 4. Table illustrating the comparison in clinical status characteristics between individuals with moderate to severe pain in the ELSA Wave 7 cohort who receive informal care versus do not receive informal care.

		No informal care received (*N* = 1133)	Receive informal care (*N* = 1045)	Regression analyses (95% CI)
CASP-19 total (mean; SD) (*N* = 1735)		36.7 (36.3–37.0)	36.3 (36.0–36.8)	MD: −0.30 (−0.82-0.23; *p* = 0.270)
CASP-19 (*N* = 1735)	0–29 points	82 (8.9)	87 (10.8)	OR: 1.24 (0.91–1.71; *p* = 0.179)
	30–57 points	845 (91.2)	721 (89.2)	
UCLA 3-item score (mean; SD) (*N* = 1780)		4.01 (3.92–4.10)	4.11 (4.01–4.21)	MD: 0.10 (−0.04-0.23; *p* = 0.149)
UCLA (*N* = 1780)	3–5 points	796 (83.3)	675 (81.9)	OR: 0.91 (0.71–1.16; *p* = 0.455)
	6–9 points	160 (16.7)	149 (18.1)	

CI – confidence intervals; MD – mean difference; OR – odds ratio; *N* – number of participants; SD – standard deviation; UCLA - University of Los Angeles.

Table 5. Table illustrating the comparison in characteristics between individuals with moderate to severe pain in the 2018 Health Survey for England cohort who receive informal care versus do not receive informal care.

		Receive informal care
N		356
Gender	Male	126 (35.4)
	Female	230 (64.6)
Age (frequency; %)	60–69	90 (25.3)
	70–79	158 (44.4)
	80–89	93 (26.1)
	90 and over	15 (4.2)
Ethnicity	White	337 (94.7)
	Asian	10 (2.8)
	Black	5 (1.4)
	Other	4 (1.1)
Marital status (frequency; %)	Single	24 (6.7)
	Married	176 (49.4)
	Separated	9 (2.5)
	Divorced	43 (12.1)
	Widowed	100 (28.1)
	Cohabitees	4 (1.1)
Lived with one or more person		201 (56.5)
NS-SEC5	Managerial and professional occupations	83 (23.3)
	Intermediate	57 (16.0)
	Low supervisory and technical	33 (9.3)
	Semi-routine	137 (38.5)
	Small employers and own account workers	40 (11.2)
	Not in occupation	6 (1.7)
Religious follower (yes; %)		297 (82.6)
Religion	No religion	63 (17.7)
	Christian	272 (76.4)
	Buddhist	2 (0.6)
	Hindu	5 (1.4)
	Jewish	2 (0.6)
	Muslin	4 (1.1)
	Sikh	1 (0.3)
	Other religion	7 (2.0)
Subjective pain grade (frequency; %)	Moderate	201 (56.5)
	Severe	122 (34.3)
	Extreme	33 (9.3)
	2 or more	295 (82.9)
	No help needed	0 (0)
Comorbidities (frequency Yes; %)	Neoplasms/Benign growth	38 (10.7)
	Endocrine/Metabolic	0 (0)
	Mental disorders	28 (7.9)
	Nervous system	47 (13.2)
	Eye	41 (11.5)
	Ear	28 (7.9)
	Heart or circulation	128 (36.0)
	Respiratory	75 (21.1)
	Digestive	43 (12.1)
	Genito-urinary	23 (6.5)
	Skin	10 (2.8)
	Musculoskeletal	264 (74.2)
	Infectious	1 (0.3)
	Blood	10 (2.8)
	Other	5 (1.4)

(continued)

Table 5. (continued)

		Receive informal care
Comorbidities (specific conditions) (Yes; %)	Diabetes	41 (11.5)
	Stroke	35 (9.8)
	Hypertension	46 (12.9)
	COPD	36 (10.1)
	Asthma	26 (7.3)
	Arthritis	182 (51.1)
	Low back pain	58 (16.3)
	Other musculoskeletal disorder	100 (28.1)
Self-reported general health	Very good	7 (2.0)
	Good	60 (16.9)
	Fair	149 (41.9)
	Bad	102 (28.7)
	Very bad	38 (10.7)
Life satisfaction	Low	80 (22.5)
	Medium	113 (31.7)
	High	109 (30.6)
	Very high	54 (15.2)
Life satisfaction score (mean; 95% CI)		6.09 (5.86–6.32)
GHQ score (mean; 95% CI)		3.12 (2.78–3.47)
GHQ cut-points (frequency; %)	0–3	228 (64.0)
	4-Above	128 (36.0)
Barthel score (mean; 95% CI)		17.23 (16.91–17.55)
EQ-5D – VAS (mean; 95% CI)		54.32 (52.21–56.42)

CI – confidence interval; COPD - chronic obstructive pulmonary disorder; GHQ – general health questionnaire; NS-SEC5 – national statistics socio-economic classification (five-item); VAS – visual analogue scale.

(MD: 17.32; $p < 0.001$) compared to those who do not receive informal care.

Discussion

The findings of this analysis indicate that people who receive care are frequently female, older aged with several medical morbidities including musculoskeletal diseases such as arthritis. People with self-reported moderate, severe or extreme intensities of chronic pain receive informal care for several diverse tasks. Most frequently these relate to IADLs such as shopping and housework. They are most frequently provided by a partner or their children. However, many also receive support from friends and neighbours. Although they demonstrate greater disability and symptoms, people who receive care do not demonstrate differences in health status either physically or mentally than those who do not.

The analysis of two nationally representative cohorts, as performed in this study, has been helpful in identifying similarities and discrepancies between the two datasets. For example, there appears consistency that care recipients who live with chronic pain are most frequently older people, females and frequently experience pain from musculoskeletal disorders. However, there are also inconsistencies between these two cohorts. For instance, care recipients from the ELSA cohort were more likely to report better self-reported general health, whereas this was lower for care recipients in the HSE cohort. Similarly, whilst perceived wellbeing was no different between care recipients and non-recipients in the ELSA cohort, care recipients reported lower life satisfaction, greater mental distress and poorer HRQoL compared to non-recipients in the HSE cohort. Previous literature offers similar uncertainties on the relationship between chronic pain and health outcomes. Bjornsdottir et al.[31] and Vartiainen et al.[32] reported that individuals with chronic pain had increased risk of reduced HRQoL. However there remains limited evidence to understand what the impact of receiving informal care is to mediate this.

This paper contributes to understanding on the care needs of people with chronic pain. Hermsen et al.[33] found that older adults with joint pain and comorbidities reported on average four care needs using the Camberwell Assessment Need for the Elderly (CANE) tool. They suggest that psychosocial needs were often unmet.[33] We were unable to explore psychosocial roles which informal caregivers or care recipients may have as data were not reported in this way by these datasets. Identifying the scope of unmet

Table 6. Table illustrating the care provision for individuals with moderate to severe pain in the 2018 Health Survey for England cohort who receive informal care.

		Receive informal care (%)
N		356
Number of activities needing help	1	61 (17.1)
	2 or more	295 (82.9)
Requirement for assistance (Yes; %)	Walking (indoors)	114 (32.0)
	Walking (outdoors)	200 (56.2)
	Stairs and steps	284 (79.8)
	Dressing	154 (43.3)
	Bathing	156 (43.8)
	Eating	50 (14.0)
	In/Out of bed	125 (35.1)
	Toileting	38 (10.7)
	Shopping	250 (70.2)
	Take medications	51 (14.3)
	Household chores	240 (67.4)
	Money and bills	88 (24.7)
Provider of assistance (Yes; %)	Partner	97 (27.3)
	Son	44 (12.4)
	Daughter	86 (24.2)
	Grandchild	17 (4.8)
	Sister/Brother	7 (2.0)
	Niece/Nephew	2 (0.6)
	Other relative	2 (0.6)
	Friend	28 (7.9)
	Neighbour	11 (3.1)
Unmet care need for specific tasks (Yes; %)	Stairs and steps	239 (67.1)
	Walking (indoors)	93 (26.1)
	In/Out of bed	85 (23.9)
	Bathing	81 (22.8)
	Dressing	80 (22.5)
	Toileting	30 (8.4)
	Take medications	21 (5.9)
	Eating	32 (9.0)
	Walking (outdoors)	71 (19.9)
	Shopping	67 (18.8)
	Household chores	79 (22.2)
	Money and bills	31 (8.7)

N – number of participants.

psychosocial care needs for both members in this dyad, with strategies to improve psychosocial wellbeing of these individuals, may be an important avenue for future study.

Usual UK care offers patient-centred interventions to support long-term management of pain and disability.[10–12] These are either through structured programmes such as the ESCAPE-Pain programme[34] or non-structured programmes incorporating elements of education, exercise, pain relief and psychological interventions, as supported by NICE.[10–12] However, in both instances, neither include caregiver interventions to support patients' symptom management. Smith et al.[35] reported the outcome of caregiver interventions to support people with chronic pain. They reported

moderate-quality evidence that caregiver interventions were effective in reducing pain in the short-term (effect size (ES): 0.16; 95% CI: −0.29 to −0.03) and low-quality evidence they could improve social functioning in the short (ES: 0.20; 95% CI: 0.02–0.38) and medium-term (ES: 0.35, 95% CI: 0.10–0.61). There was low-quality evidence that caregiver interventions improved patient-perceived coping in the short-term (ES: 0.81; 95% CI: 0.39–1.23). This importantly suggests that caregiver interventions, when offered, may confer benefit on the recipient of informal care.[35] The findings from this study have provided insights into the profile of people with chronic pain who need (and receive) informal care. Health professionals may therefore be cognisant of their potential role in
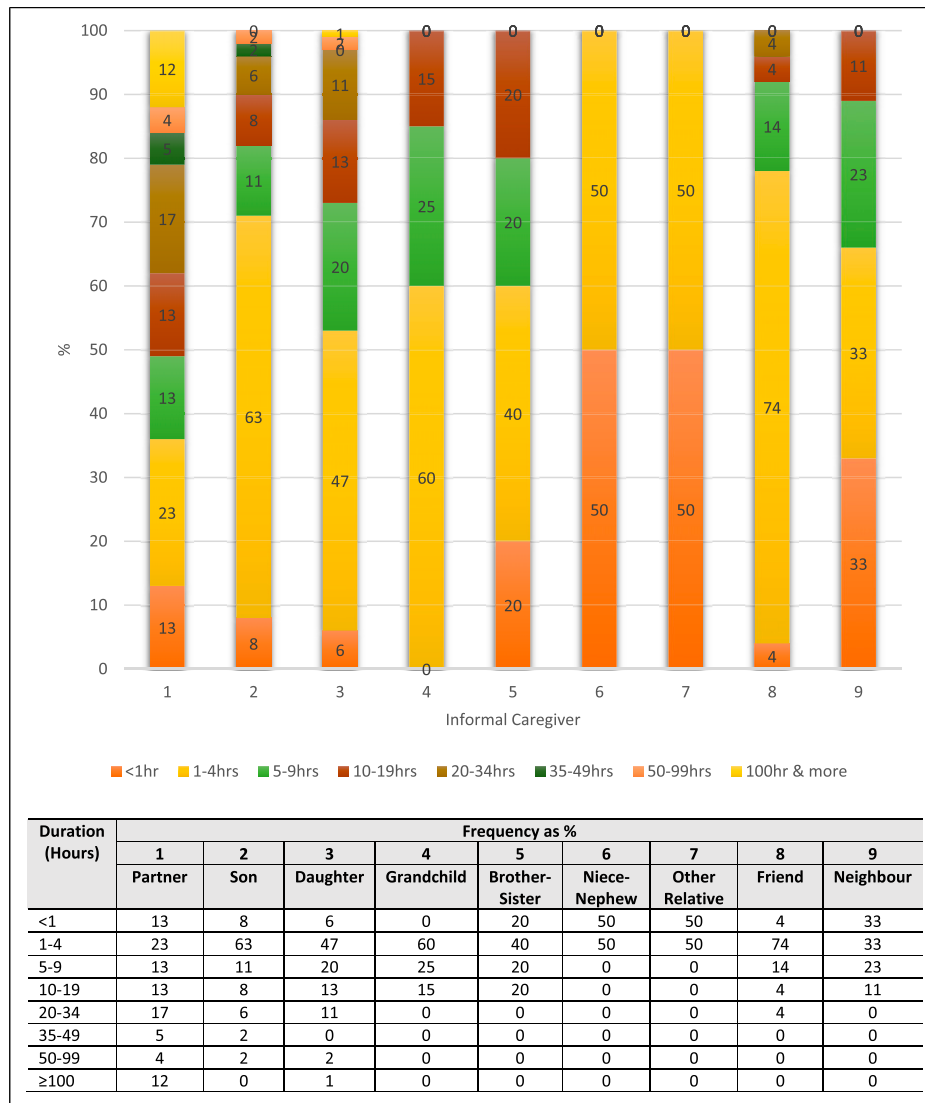
Figure 3. Stack bar chart of hours of informal care provided by caregiver for person with moderate to severe pain reported in the 2018 Health Survey for England cohort.

Table 7. Table illustrating the comparison in clinical status characteristics between individuals with moderate to severe pain in the 2018 Health Survey for England cohort who receive informal care versus do not receive informal care.

		No informal care received	Receive informal care	Regression analyses (95% CI)
Life satisfaction score (mean; 95% CI)		7.53 (7.29–7.77)	6.09 (5.86–6.32)	MD: −1.44 (−1.79 to −1.09; *p* < 0.001)
GHQ score (mean; 95% CI)		1.28 (0.97–1.59)	3.12 (2.78–3.47)	MD: 1.84 (1.34–2.35; *p* < 0.001)
GHQ cut-points (frequency; %)	0–3	190 (87.2)	228 (64.0)	OR: 0.26 (0.17–0.41; *p* < 0.001)
	4-Above	28 (12.8)	128 (36.0)	
Barthel score (mean; 95% CI)		20.00 (20.00–20.00)	17.23 (16.91–17.55)	MD: −2.77 (−3.18 to −2.36; *p* < 0.001)
EQ-5D – VAS (mean; 95% CI)		71.63 (69.57–73.70)	54.32 (52.21–56.42)	MD: −17.32 (−20.45 to −14.18; *p* < 0.001)

CI – confidence intervals; GHQ – general health questionnaire; MD – mean difference; OR – odds ratio; VAS – visual analogue scale.

discussing care and support needs, not only with patients but also with caregivers, who may support people living with chronic pain.

The analyses performed were based on cohorts from England. Whilst there is some diversity in the national population, there was limited diversity reported in these cohort. For instance, less than two percent of this cohort were from non-white ethnicities. This is an important consideration in relation to ethnicity, culture and beliefs when the national average of non-white people in England is 14%.[36] People with differing beliefs about pain and its management may express this symptom differently.[37,38] Similarly, some cultures have contrasting views on the responsibility of family and friends to caregiving[39] and be more likely to live nearby to family members which may facilitate caregiving.[40] Such analyses to explore the relationship between cultural differences and caregiving for pain would be valuable.

The results offer important research implications. Firstly, there remains uncertainty as to what can be offered as informal care to support people living with chronic pain. The results indicate a need to better support these individuals. Currently the JOINT SUPPORT trial[41] has begun to investigate a caregiver intervention for people with chronic musculoskeletal pain. This is aimed to better understand whether a caregiver programme can modify outcomes both for individuals with pain and their caregivers. Secondly, the findings offer a 'mixed' interpretation on the health status of people living with chronic pain who receive or do not receive informal care. Whilst our findings indicate that those who receive informal care often have greater disability to require assistance in activities, these individuals, based on the ELSA cohort, have similar health and wellbeing outcomes to individuals who do not receive assistance. Conversely the HSE cohort suggests that those who receive informal care, with equal levels of disability, have poorer health outcomes. Interpretations can be offered for where effective informal caregiving may 'equal out' the perceived poorer health status, thereby providing comparable health status. The HSE cohort may be interpreted to have greater disability and pain severity reported by people receiving care, reflected in poorer health status. In that instance, the provision of informal care appears not to modify this. Given this variability in outcome, further longitudinal evaluation of diverse health and wellbeing outcomes, is warranted.

From a clinical perspective, this epidemiological study highlights that people with chronic pain frequently receive support on a wide variety of activities, at varying intensities. Whilst management programmes frequently focus on 'patients', clinicians should also consider those who support them. Where appropriate, educating caregivers on management skills and treatment regimens to promote patient adherence and understanding, should be considered. As highlighted, further research is being undertaken,[41] to provide an evidence-base on-which to implement such programmes.

This analysis offers several strengths. Firstly, this is the first analysis of informal care receipt for people with chronic pain. It is based on two large and representative English cohorts, thereby offering generalisable findings to this population. The interpretation of two cohorts provides the ability to assess for similarities and differences to make firmer conclusions on the research question. However, the study also presents with four weaknesses. Firstly, there were limited data to determine whether individuals who received care required this principally for chronic pain or whether this was for another condition. Whilst the comorbidity data indicates that musculoskeletal pain and disorders were the most prevalent medical presentation in both datasets, medical conditions such as respiratory, neurological, or mental health conditions may have impacted on the reasoning why people needed informal care. Secondly, it was not the purpose of this analysis to assess whether care receipt changed over time. Whilst this would be helpful to determine whether this challenge is static or progressive, the use of the latter phases of data collection waves for the respective cohorts meant a longitudinal analysis was not feasible. Thirdly, the data reported were self-reported, therefore offering potential issues in recall or social desirability bias.[42] There remains stigma regarding how people report the level of care they provide or receive.[43] Further prospective means of assessing caregiving requirements and receipt would be helpful to determine such potential biases. Finally, whilst assessments were made on socio-economic status, religion and ethnicity, there was limited data provided through the datasets on culture and attitudes to caregiving. Given these may influence the types of activities, frequency and relationship with care recipients,[44,45] future assessment in indicated to consider these potentially important factors.

Conclusions

People living with chronic pain frequently receive informal care and support from an array of different people. This is a diverse level of support both in the

types of tasks supported and the time commitment offered by informal caregivers. This analysis has indicated that whilst it may be possible to characterise people living with chronic pain who receive informal care, there is uncertainty on the impact of informal caregiving on their health and wellbeing. There is valuable learning to be now made on how best to support both care recipients and informal caregivers, to ensure their health and quality of life is promoted whilst living with this long-term condition.

Contributorship

All authors contributed to the design, conduct, analysis and preparation of the drafts of this paper. TS and AC lead the analysis. All authors approve the final version of the paper.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

ELSA Wave 7: South Central – Berkshire Research Ethics Committee on 23rd September 2015 (Reference: 15/SC/0526). HSE2019-HSE2019: East Midlands Nottingham 2 Research Ethics Committee in 2015 (Reference no. 15/EM/0254).

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Informed consent

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Guarantor

TS. The corresponding author will act as guarantor. They had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Data availability statement

All data are under the supervision of the corresponding author and can be made available on reasonable request.

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