

Original Article

Living With an Older Person Dying From Cancer, Lung Disease, or Dementia: Health Outcomes From a General Practice Cohort Study

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Abstract

Context. Increasing numbers of people will die from chronic disease. Families contribute significantly to end-of-life care, but their role may not be recognized.

Objectives. To 1) establish the proportion of older cohabitants identified in primary care as “carers”; 2) describe demographic and lifestyle characteristics of cohabitants of people terminally ill with cancer, dementia, and chronic obstructive pulmonary disease (COPD); 3) describe their health a year before and after bereavement; and 4) compare health outcomes between cohabitants of people dying with cancer, COPD, or dementia.

Methods. Retrospective cohort study using a U.K. primary care database (The Health Improvement Network) of 13,693 bereaved cohabitants (a proxy marker for being a carer), aged 60 years or older of people dying from cancer, COPD, or dementia. Characteristics were described one year before and after bereavement. We compared cancer, COPD, and dementia cohabitant outcomes using incidence rate ratios one year before and after bereavement and calculated mortality risk after bereavement.

Results. A total of 6.9% of cohabitants were recorded as carers. Health outcomes differed little between the three groups of cohabitants in the year before or after bereavement. The proportion of cohabitants with six or more consultations increased the year after bereavement (cancer cohabitants 16.0% to 18.8%, COPD cohabitants 17.8% to 20.4%, and dementia cohabitants 15.5% to 17.5%). At postbereavement (follow-up median 3 years, interquartile range 1.3–5.4), we found no mortality differences between the three groups.

Conclusion. Recording of carers of terminally ill people was suboptimal. Cause of bereavement produced few differential effects on health outcomes or mortality. *J Pain Symptom Manage* 2016;■:■–■. © 2016 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Key Words

Caregivers, palliative care, bereavement, primary health care, epidemiology

Introduction

Informal and family carers contribute greatly to health and social care. There are approximately 65.7 million carers in the U.S. and 6.5 million in the U.K.^{1,2} In the U.K., since 2010, carers' financial contribution outstripped the total cost of the National Health Service (£98.8 billion per annum).¹

A variety of terms encompass this role, for example, “carer,” “informal carer,” or “family carer.” The U.K. National Institute for Health and Clinical Excellence states “carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management.”³ We use the term “carer” in this article.

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Caring for a friend or relative with terminal disease is often willingly undertaken and can be a positive experience but is demanding,^{4,5} particularly because carers of people with long-term illness are more likely to be older.⁶ Studies have mainly focused on psychological outcomes such as depression,⁶ and although carers describe poor self-perceived health,⁷ there has been little research on specific health outcomes such as stroke or diabetes.

The death of a spouse may increase mortality, particularly in the first six months after bereavement⁸ or after an unexpected death.⁹ However, there are few longitudinal studies on carers' health when the care recipient is still alive but entering the terminal phase. As policies to increase the number of deaths in patients' own homes become effective, demands on carers will increase.¹⁰ By 2030, the worldwide annual number of deaths is predicted to rise from 58 to 74 million. Research has focused on those caring for someone with cancer,^{11–13} but diseases associated with physical and cognitive frailty will contribute most to this increase.¹⁴

Three “trajectories of dying” have been described, cancer, organ failure (such as chronic obstructive pulmonary disease [COPD]), and frailty (including dementia).¹⁵ In each trajectory, there will be different health, functional, and psychological problems for which patients will require support from family and friends.^{16,17} In addition, each trajectory may have a different impact on carers; for example, longitudinal and qualitative studies have demonstrated how the course of COPD is lengthy and beset with considerable uncertainty.^{18,19} Despite changes in the cause of death, palliative care services still mainly care for those with cancer^{11,20,21}; we do not know whether different disease trajectories and inequitable access to palliative care and social support have a differential impact on carer outcomes.¹¹

At the end of life, care is often provided to the dying person by a complex and diffuse network of both family and friends²²; however, at least half of carers provide care in the same household.¹ They have poorer quality of life and worse health than carers who do not live with the care recipient.⁶ A challenge in conducting research is that family members do not always identify themselves as carers; studying cohabees of people dying from a progressive disease may overcome this lack of recognition. We need to better understand, in representative populations, the health impact of caring over the latter stages of a terminal illness and into bereavement in noncancer diseases.⁶

Aims and Objectives

Our aim was to undertake a retrospective national cohort study to describe the demographic

characteristics, health outcomes, and primary care service use of cohabees of people dying with cancer (lung or colorectal), dementia, or COPD during the year before and after bereavement. Our specific objectives were to 1) establish the proportion of cohabees identified by their general practitioner (GP, family practitioner) as “carers”; 2) describe demographic and lifestyle features of adult cohabees within two-adult households, of people with cancer, dementia, and COPD who are approaching the end of life; 3) describe the prevalence and incidence of a range of physical and psychological health outcomes and primary care service use in the cohabees in the time periods covering one year before and after bereavement; and 4) compare differences in health outcomes (including mortality after bereavement) between cohabees of people dying with cancer, COPD, and dementia.

Methods

Data Source

In the U.K., the majority of the population is registered with a GP who provides primary care, free at the point of use. Over 500 general practices contribute data to The Health Improvement Network (THIN), a primary care database containing over 12 million patients, including 3.6 million active patients (<http://www.csdmruk.imshealth.com/>). Prescriptions are entered into the system automatically, and GPs record symptoms and diagnoses using the Read classification system.²³ THIN is broadly representative of the U.K. population.²⁴

Ethics

The THIN scheme was approved by the National Health Service South-East Multicenter Research Ethics Committee in 2002. Our study received approval from the Scientific Review Committee (August 6, 2013 reference 13-040).

Population

We identified individuals cohabiting with someone who had died with cancer, dementia, or COPD. For each practice, we used data from when levels of computer usage were considered to be acceptable, and death recording was complete.^{25,26} For this analysis, we used being a cohabees as a “proxy” for being a carer, making the assumptions that 1) the majority of these dyads would be spouses or partners and 2) a spouse or partner of a patient who died with cancer, dementia, or COPD would be fulfilling a caring role in the last year of the patient's life and, therefore, “exposed” long term to the stresses that this brings.

Using a family number (identifier) in THIN that indicates those in the same household, we identified households where there had been a death between 2003 and 2011 in people aged 40 years or older who had a diagnosis of cancer, dementia, or COPD, according to Read code lists developed using published methodology.²⁷ To ensure that we did not select those who had a previous diagnosis of cancer now in remission, cancer diagnoses were restricted to those recorded within five years before the death of the patient. We included the two most common, non-sex-related cancers, lung and colorectal.²⁸

Selected individuals were those in households that contained one other adult (i.e., the cohabitee) before the death of the patient. This was to exclude instances where the family number represented blocks of flats or residential homes. We also excluded households with an age gap of greater than 15 years to remove cohabitees living with dying adult children or parents.

The cohort of cohabitees was further restricted to those who had been registered at the practice for at least one year by the date of bereavement; this was to ensure a full year of prebereavement data. Data on individuals in the cohabitee cohort were included from a year before bereavement until up to a year after bereavement. Those individuals for whom information on area-level deprivation was not available were excluded (2%). Cohabitees aged 60 years or older at bereavement were included in the study.

Characteristics and Outcomes Under Consideration

For the cohabitee cohort, we determined the following sociodemographic and behavioral characteristics: age at the time of bereavement, gender, gender of the deceased person they were cohabiting with, area-level deprivation, excess alcohol use, and current smoking status. Area-level deprivation was available in the data set as quintiles of the Townsend score; the Townsend score is linked to a patient's postcode, based on levels of unemployment, car ownership, home ownership, and household overcrowding. Excess alcohol use, in the three years before bereavement, was defined as either the presence of a Read code indicating heavy alcohol use, or a record of weekly intake exceeding the recommended U.K. upper limit of 14 units in women and 21 units in men. One U.K. unit of alcohol is equivalent to 10 mL (8 g) of ethanol. Individuals were defined as smokers if their recorded smoking status closest to the date of bereavement (and within three years) was as a current smoker.

We developed a Read code list to determine whether the cohabitees had been identified as carers in their medical records. We used Read code lists for hypertension, stroke, and transient ischemic attack,

coronary heart disease, diabetes, and cancer to determine whether there was any record of each of these outcomes in the primary care records of the cohabitees during the year before and the year after bereavement. Primary care prescription records, mapped to British National Formulary chapters, were used to determine whether cohabitees had been prescribed antidepressants, hypnotics, or anxiolytics in the year before and the year after bereavement: only newly initiated prescriptions were considered. The number of surgery consultations in primary care was obtained for each cohabitee in the year before and the year after bereavement.

Individuals were followed in this analysis until they transferred out of the practice or until the latest date that data from the practice were available. This allowed consideration of longer term mortality after bereavement. Before and after bereavement, we compared outcomes across the three groups of the cohabitee cohort defined by the condition that their cohabitee had died with: cancer, dementia, or COPD.

Statistical Analyses

We used Poisson regression for incidence rate ratios (IRRs) for the physical and psychological morbidities comparing the dementia and COPD groups with the cancer group, adjusting IRRs for sex, age, area-level deprivation, smoking status, and alcohol use. For mortality, we calculated adjusted hazard ratios using multivariable Cox proportional hazards modeling, including sex, age, area-level deprivation, smoking status, and alcohol use. Clustering by practice was accounted for by random-effects Poisson regression. Analyses were performed using Stata 13 (StataCorp LP, College Station, TX).

Results

Cohort Selection

We identified 79,946 individuals aged 40 years or older, who had died with cancer (lung or colorectal), dementia, or COPD between January 2003 and January 2013. After excluding those who did not have a cohabitee (the largest excluded group 61,935) and those with less than one year of follow-up before bereavement, no Townsend score available or an age difference with the cohabitee of more than 15 years, we identified a cohort of 13,693 bereaved cohabitees (Fig. 1).

Cohort Characteristics

Cohabitees of those who died with dementia were older (median age 82 years, interquartile range [IQR] 77–86) than those who died with cancer (median age of cohabitee 75, IQR 69–80)

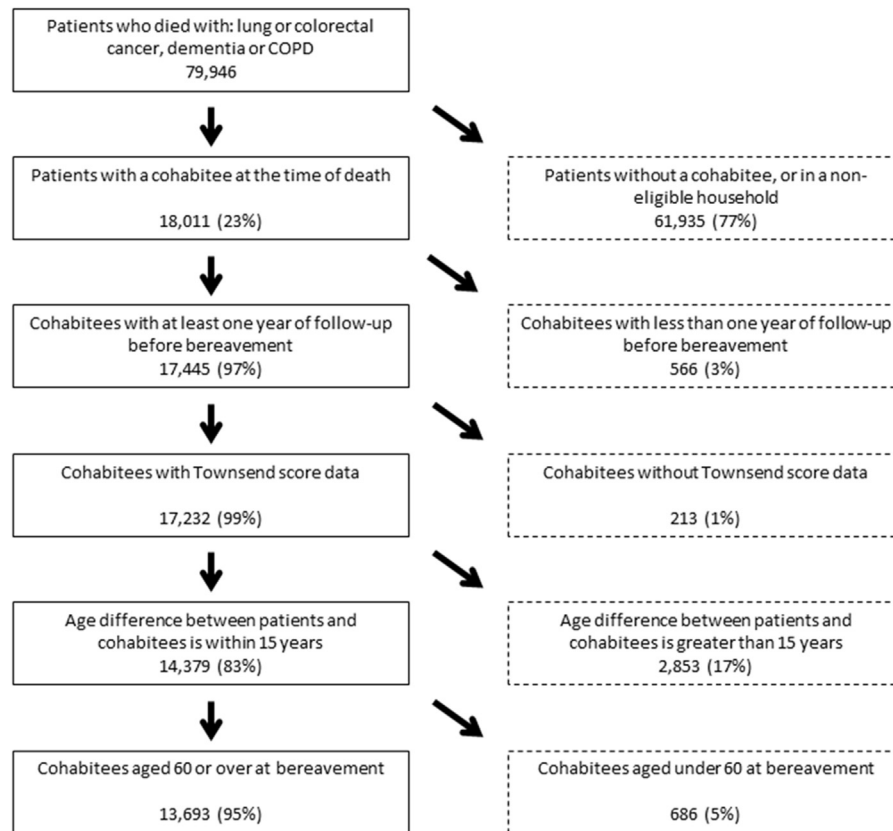


Fig. 1. Selection of the cohabeete cohort.

or COPD (median age of cohabeete 77, IQR 71–82). Over two-thirds of cohabitees were female and over 95% were in households of male/female pairs (Table 1). Excess alcohol use was slightly higher in cohabitees of those dying with cancer or COPD

(2.6% and 2.7%) compared to cohabitees of those dying with dementia (1.7%). More cohabitees of patients dying with of COPD (15%) were smokers than cohabitees of those dying with cancer and dementia (12% and 6.7%).

Table 1
Characteristics of Cohabeete Cohort at Time of Bereavement

Cohabeete Characteristic	Patient Diagnosis		
	Cancer	COPD	Dementia
Number	4248	6041	3404
Age median (IQR)	75 (69–80)	77 (71–82)	82 (77–86)
Women <i>n</i> (%)	2935 (69)	4304 (71)	2150 (63)
Male/female pairs <i>n</i> (%)	4185 (99)	5928 (98)	3230 (95)
Townsend deprivation quintile <i>n</i> (%)			
1 (least deprived)	1080 (25)	1254 (21)	898 (26)
2	1021 (24)	1334 (22)	869 (26)
3	903 (21)	1313 (22)	743 (22)
4	801 (19)	1290 (21)	561 (16)
5 (most deprived)	443 (10)	850 (14)	333 (10)
Recorded excess alcohol use ^a	109 (2.6)	163 (2.7)	56 (1.7)
Recorded as current smokers ^{a,b}	516 (12)	879 (15)	227 (6.7)
Recorded carer status of cohabeete			
Before bereavement: recorded as being a carer <i>n</i> (%)	137 (3.2%)	290 (4.8%)	523 (15.4%)
After bereavement: recorded as no longer being a carer <i>n</i> (%)	23 (0.5%)	63 (1.0%)	85 (2.5%)

COPD = chronic obstructive pulmonary disease; IQR = interquartile range.

^aIn the three years before the death of the patient.

^bSmoking data recorded for 3465 (82%) in the cancer group, 4934 (82%) in the COPD group, 2694 (79%) in the dementia group.

Identification of Cohabitees as Carers

Overall, 6.9% of cohabitees were recorded as being carers by the GP; 15.4% of cohabitees of those with dementia, but fewer of those who died with cancer or COPD (3.2% and 4.8%, respectively) (Table 2).

Health Before Bereavement

In the year before bereavement, we found few differences in health between cohabitees of people dying from cancer, dementia, or COPD, as indicated by the prevalence of primary consultations for hypertension, stroke or transient ischemic attack, coronary heart disease, and cancer (Table 2). Similarly, there were few differences in prescriptions of psychotropic medications.

Health After Bereavement

In the year after bereavement, consultations for the health outcomes examined remained similar between cohabitees of those who had died from cancer, COPD,

or dementia. However, there was an increase in prevalence of prescriptions for antidepressants, hypnotics, and anxiolytics for all groups of cohabitees.

The proportion of carers consulting on more than six occasions rose slightly in all three groups (from 16.0% to 18.8% in cohabitees of people dying with cancer; from 17.8% to 20.4% in cohabitees of those dying with COPD; and from 15.5% to 17.5% in cohabitees of those dying with dementia) (Table 2).

Incidence of Health Outcomes Before and After Bereavement

Before and after bereavement, there were no differences in unadjusted and adjusted IRRs for consultations for hypertension, coronary heart disease, diabetes, and cancer in cohabitees of patients with cancer and those of people with COPD and dementia (Fig. 2). There were no significant differences in prescribing of psychotropic medications between the three groups (Fig. 2).

Table 2
Health and Service Use Outcomes in Cohabitees of People With Cancer, COPD, and Dementia, Before and After Bereavement

Outcome	Patient Diagnosis		
	Cancer	COPD	Dementia
Number	4248	6041	3404
Year before bereavement			
Patients with consultations for			
Hypertension	712 (16.8%)	1058 (17.5%)	558 (16.4%)
Stroke or TIA	46 (1.1%)	71 (1.2%)	59 (1.7%)
Coronary heart disease	74 (1.7%)	159 (2.6%)	82 (2.4%)
Diabetes	487 (11.5%)	717 (11.9%)	351 (10.3%)
Cancer	141 (3.3%)	196 (3.2%)	127 (3.7%)
Patients with new ^a prescriptions for			
Antidepressants	248 (6.9%)	324 (6.5%)	220 (7.9%)
Hypnotics	193 (4.9%)	184 (3.3%)	133 (4.4%)
Anxiolytics	132 (3.3%)	161 (2.8%)	88 (2.7%)
Number of primary care consultations			
Median (IQR)	3 (1–5)	3 (1–5)	3 (1–5)
Number (%) with more than six	679 (16.0%)	1073 (17.8%)	528 (15.5%)
Year after bereavement			
Patients with consultations for			
Hypertension	718 (16.9%)	1091 (18.1%)	546 (16.0%)
Stroke or TIA	40 (0.9%)	70 (1.2%)	51 (1.5%)
Coronary heart disease	82 (1.9%)	153 (2.5%)	77 (2.3%)
Diabetes	471 (11.1%)	687 (11.4%)	331 (9.7%)
Cancer	162 (3.8%)	237 (3.9%)	164 (4.8%)
Patients with new ^b prescriptions for			
Antidepressants	395 (11.3%)	617 (12.7%)	260 (9.8%)
Hypnotics	352 (9.2%)	625 (11.5%)	201 (6.7%)
Anxiolytics	237 (5.9%)	384 (6.7%)	159 (5.0%)
Number of primary care consultations			
Median (IQR)	3 (1–6)	3 (1–6)	3 (1–5)
Number (%) with more than six	798 (18.8)	1232 (20.4)	596 (17.5)

COPD = chronic obstructive pulmonary disease; IQR = interquartile range; TIA = transient ischemic attack.

^aIncluded patients did not receive a prescription between two and one years before bereavement. Antidepressants analysis: 3609 included patients in the cancer group, 5008 in the COPD group, 2773 in the dementia group. Hypnotics analysis: 3950 in the cancer group, 5527 in the COPD group, 3048 in the dementia group. Anxiolytics analysis: 4053 in the cancer group, 5767 in the COPD group, 3247 in the dementia group.

^bIncluded patients did not receive a prescription in the year before bereavement. Antidepressants analysis: 3494 included patients in the cancer group, 4867 in the COPD group, 2662 in the dementia group. Hypnotics analysis: 3757 in the cancer group, 5343 in the COPD group, 2915 in the dementia group. Anxiolytics analysis: 3921 in the cancer group, 5606 in the COPD group, 3159 in the dementia group.

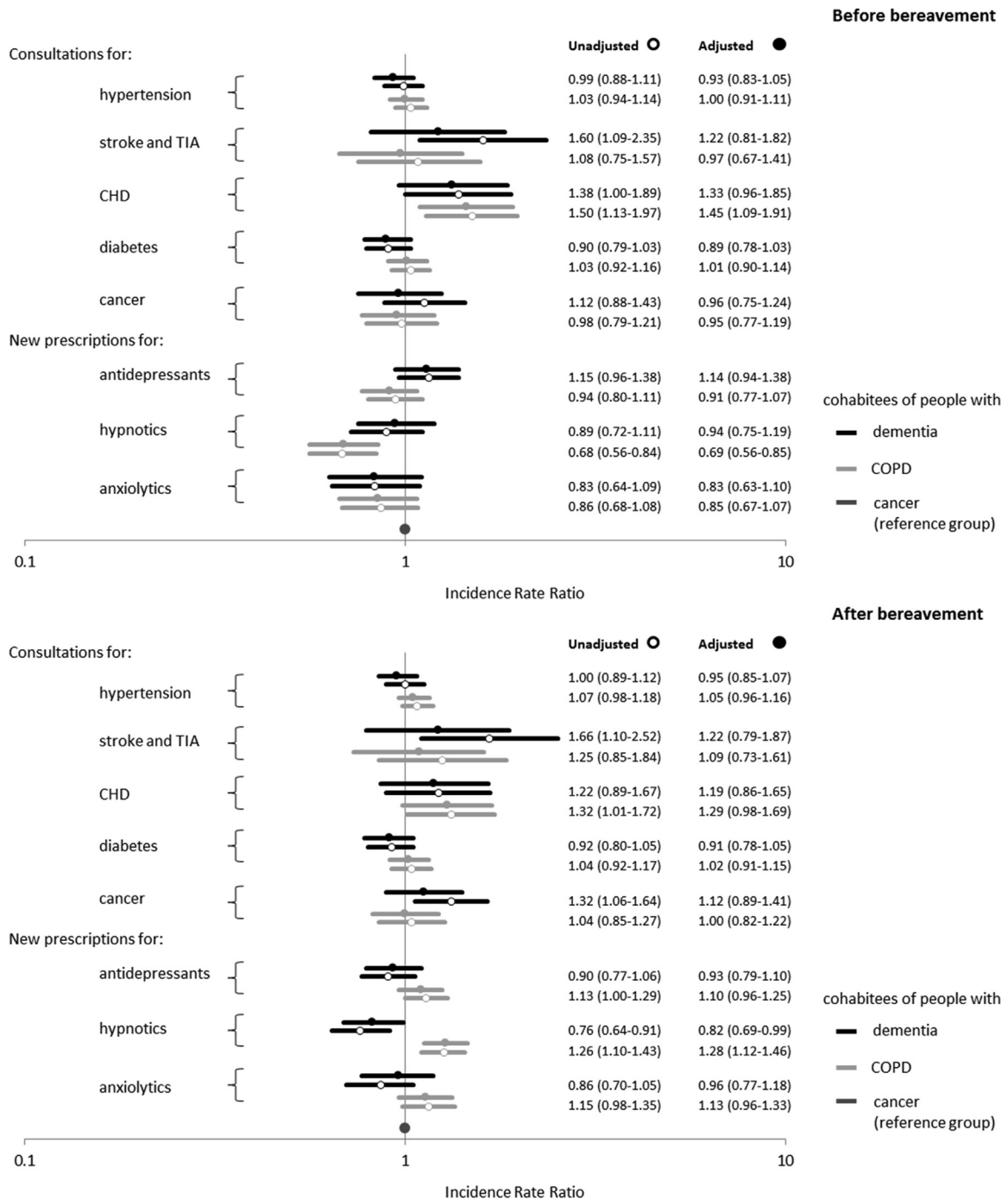


Fig. 2. Results from univariable and multivariable Poisson regression models of consultations and new prescriptions in the cohabees cohort by patient diagnosis. Multivariable models additionally include sex, age at bereavement, Townsend deprivation score quintile, excess alcohol use before bereavement, smoking status before bereavement. Clustering by practice was accounted for by random-effects Poisson regression. TIA = transient ischemic attack; CHD = coronary heart disease; COPD = chronic obstructive pulmonary disease.

In adjusted analyses, cohabees of people with dementia were less likely to receive new prescriptions for hypnotics after bereavement (IRR 0.82, 95% CI 0.69–0.99) compared to cohabees of people with COPD (IRR 1.28, 95% CI 1.12–1.46) or cancer (reference group).

Mortality

Follow-up was available for a median (IQR) of 3.0 (1.3–5.4) years after bereavement, during which 2222 (16.2%) died (Table 3). The largest proportion of deaths was in cohabees of those with dementia. The risk of death was higher in the COPD and

Table 3
Mortality After Bereavement

Statistic	Patient Diagnosis		
	Cancer	COPD	Dementia
Number	4248	6041	3404
Number (%) deaths	535 (12.6)	1020 (16.9)	667 (19.6)
Unadjusted hazard ratio	1	1.35 (1.22–1.50)	1.84 (1.64–2.06)
Adjusted hazard ratio	1	1.13 (1.02–1.26)	1.10 (0.97–1.24)

COPD = chronic obstructive pulmonary disease.

Adjusted hazard ratio from a multivariable Cox proportional hazards model including sex, age, area-level deprivation, smoking status, and alcohol use. *P*-value for test of difference between groups: <0.001 in univariable model, 0.064 in multivariable model.

dementia groups compared to the cancer group, with hazard ratios 1.35 (95% CI 1.22–1.50) for the COPD group and 1.84 (95% CI 1.64–2.06) for the dementia group. However, after adjustment for confounders, there was no significant difference in mortality risk between the three groups.

Discussion

We identified a cohort of over 13,000 bereaved cohabitants, but few were recorded as being carers by their GPs. There are complex reasons why carers of those reaching the end of life may not be formally identified. The term “carer” is one imposed by service providers and may not be accepted or felt relevant by the carers themselves. They may not need help when they are asked and only seek assistance at a time of crisis. They may feel guilty or ambivalent about “not coping,” or have difficulty in acknowledging how serious the illness is.^{29,30}

A higher proportion of cohabitants of people with dementia were recognized as carers. This may have been driven by policy, in particular the English National Dementia Strategy,³¹ which promotes the recognition of dementia in primary care. After this, GPs were incentivized to create a register of patients diagnosed with dementia and address their needs.

We found little difference between the three groups of cohabitants in health or psychological outcomes in the year before or after bereavement. After bereavement, there was an increase in prescriptions for antidepressants, hypnotics, and anxiolytics. There was an increase in primary care consultations in the year after bereavement but no difference in longer term mortality risk between the three groups. Most previous work on caring at the end of life has been in cancer where it is often stated that there is a more predictable disease trajectory and access to services is better.^{10,20,21} It has been suggested that carers of people with a more

unpredictable disease trajectory (such as dementia or COPD) may have poorer access to palliative care support¹⁰ and experience higher stress and worse health. This is particularly emphasized in dementia where carers manage behavioral disturbance.³² However, we found that all three groups of cohabitants had similar health outcomes.

There are a number of possible explanations for our findings. Although it is assumed it is more stressful caring for a person with dementia, the burden of caring for someone with cancer or COPD may be as great, but different in nature. A person dying with COPD may have significant physical nursing needs at home.²¹ Our results also may be explained by the “healthy caregiver effect”: healthier older people are selected into a caregiving role.³³ Carers who could not cope may have already moved the care recipient to a care home. In addition, those cohabitants who were in poor health may have died before their care recipient and these were excluded. Thus the carers in our cohort may have had similar levels of overall “resilience” leading to fewer differences in health outcomes between the groups. Caring is a highly individual experience, and studies of carers of people with dementia and cancer suggest that it is not specific symptom, but carers’ appraisal of the situation that determines how they cope.^{34,35} It also may be that more systemic factors, such as the availability of support, influence health after bereavement rather than the cause of bereavement itself.⁶

The proportion of cohabitants having more than six consultations per year rose slightly in all three groups after bereavement. This has been found in previous studies,¹³ and the effect is maintained up to five years after the loss.³⁶ We identified spouse pairs who are, by selection for this study, attending the same general practice; staff are likely to be aware of the bereavement and may have offered increased support.³⁷ It has been suggested that carers of those dying from cancer receive better care because they are supported by hospices.³⁸ Our findings suggest that cohabitants of those dying from cancer, COPD, and dementia received similar levels of primary care support.

Bereavement is emotionally stressful and a significant proportion of carers develop complicated grief, depression, or anxiety.³⁹ We found an increase in prescriptions for antidepressants, hypnotics, and anxiolytics, in keeping with findings that one in five older people will receive a new psychotropic drug prescription in the year after bereavement.⁴⁰ We did find, however, that carers of people who died with dementia had a lower rate of new prescriptions for hypnotics. It may be that their sleep improved after bereavement as they no longer had to manage the nocturnal disturbance that occurs in dementia, or this may be artifact

as cohabiters of people with dementia may have already been prescribed hypnotics before bereavement and, therefore, in receipt of fewer new prescriptions after bereavement.

We found no significant difference in mortality between our three groups of cohabiters. In unadjusted analysis, mortality risk was significantly increased in cohabiters of those with dementia (hazard ratio 1.84, 95% CI 1.64–2.06); however, controlled analysis suggested that older age mainly influenced this. Despite consistent findings that caregivers have poorer health, the literature on caregiver mortality is contradictory. Two large studies^{41,42} found that spouses experienced significantly increased risk of mortality. However, others demonstrate reduced mortality risk in caregivers.^{13,33,43,44} This may, in part, be a result of the “healthy caregiver effect,” or the fact that long-term chronic disease of any type gives caregivers the opportunity to adapt, reflect, and act on their own health. In addition, sudden unexpected bereavement has a greater relative mortality impact than bereavement preceded by chronic disease.⁹

Strengths and Limitations

Using a large general practice database that represents routine clinical practice in U.K., primary care avoids the recruitment challenges, selection, and recall bias inherent in many longitudinal cohort studies of carers. In particular, those carers who are most stressed by their role are less likely to participate in research.⁴⁵ Our methodology overcomes this issue. We assumed that cohabiters are fulfilling a caring role; we have used being a cohabiter as a “proxy” for being a carer and thus assumed that they are exposed to the stresses this brings. We cannot be sure that all cohabiting pairs were spouses. However, the contrasting sex of the pairs (99% male/female pairs for cancer cohabiters and 98% for COPD cohabiters) suggests that this is the case. This limitation would occur in all three of the groups of cohabiters that we compared, but, slightly fewer of the dementia cohabiters were in male/female pairs (95%). This may reflect the older age of this cohort and that some of these cohabiters may have been siblings who had moved in together because of prior spouse bereavement, increasing dependency or following the diagnosis of dementia. Dementia is underrecognized in primary care in the U.K.^{46,47} Thus, it may be that our cohort was more likely to contain those whose dementia was recognized because of problematic symptoms or carer stress. For COPD, there is evidence that observed prevalence in the THIN database is similar to national data.⁴⁸ The recording of death in the THIN database has been validated.⁴⁹ We identified people who died with a particular diagnosis and studied outcomes in their

cohabiters, but we cannot be sure that cancer, COPD, or dementia was the actual cause of death. There may have been residual confounding, and we may not have adjusted for all variables influencing our outcomes. We selected a limited number of health outcomes based on the commonest causes of death and comorbidity in the U.K.⁵⁰ Future studies could examine a wider range of carer health outcomes.

Implications

In general practice, we may underestimate the number of family and other close persons caring for a dying person. Day-to-day, GPs may acknowledge this and support carers, but, if not coded, this work is not acknowledged by services and policy makers. Identifying carers is a key step toward providing appropriate health care, for example, supportive interventions may improve carers’ psychological distress.¹²

Our finding that cohabiter health was similar both before and after bereavement, whether the cared-for person died of cancer, COPD, or dementia, suggests that these diseases, with differing trajectories of decline, produce similar effects on carers. Complex interventions that involve proactively seeking carers in primary care are in development,³⁰ but these may need to be implemented via top-down policy incentives.⁴⁵

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