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Association between primary care contacts, continuity of care and identification of palliative care needs with hospital utilization among people dying with dementia: a population-based cohort study

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Title:

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Abstract

Background: Reducing hospital admissions among people dying with dementia is a policy priority.

Aim: To explore associations between primary care contacts, continuity of primary care and identification of palliative care needs with unplanned hospital admissions among people dying with dementia.

Design & setting: Retrospective cohort study using the Clinical Practice Research Datalink linked with hospital records and Office for National Statistics data. Adults (>18 years) who died between 2009-2018 with a diagnosis of dementia.

Methods: We evaluated associations between GP contacts, the Herfindahl Hirschman continuity of care (CoC) score and palliative care needs identification before the last 90 days of life with multiple unplanned hospital admissions in the last 90 days using random-effects Poisson regression.

Results: We identified 33714 decedents with dementia: 64.1% female, mean age 86.6 (SD 8.1), mean comorbidities 2.2 (SD 1.6). 1894 (5.6%) had multiple hospital admissions in the last 90 days of life (increase from 4.9% (95% CI 4.2-5.6) in 2009 to 7.1% (95% CI 5.7-8.4) in 2018). Participants with more GP contacts had higher risk of multiple hospital admissions (IRR 1.08, 95% CI 1.05-1.11). Higher CoC scores (IRR 0.79, 95% CI 0.68-0.92) and identification of palliative care needs (IRR 0.66, 95% CI 0.56-0.78) were associated with lower frequency of these admissions.

Conclusions: Multiple hospital admissions among people dying with dementia are increasing. Higher CoC and identification of palliative care needs are associated with a lower risk of multiple hospital admissions in this population, and might help prevent these admissions at the end of life.

Keywords:

Dementia, End-of-life, Family Practice, Palliative Care, Primary Health Care, Hospitalization

How this fit

People with dementia are at high risk of multiple hospital admissions at the end of life and preventing these admissions is a policy priority. This study found that people with dementia who had better continuity of care with GPs were less likely to have multiple hospital admissions in the last 90 days of life, in particular if they lived at home and had multiple comorbidities. People living in care homes and with an identification of palliative care needs in their primary care records were less likely to experience these admissions.

Introduction

Dementia is one of the leading causes of death in high-income nations,[1] and the number of people dying with dementia requiring symptom management is projected to increase.[2, 3] It is essential, for patients and the system, to better understand how to provide high quality end-of-life care for this population.

People with dementia experience a rapid increase in symptoms,[4, 5] emergency department visits[6, 7] and hospital admissions in the last year of life.[8, 9] Transitions to hospital among people dying with dementia have been associated with markers of poor-quality end-of-life care,[10] and poor health outcomes such as delirium, falls, cognitive and functional decline.[11-13] Multiple hospital admissions in the last 90 days of life has been suggested as an indicator of poor end-of-life care in people with dementia.[14, 15]

Primary care services, including General Practitioners (GPs), nurses or other health care services provided in the community, are likely to contribute to reducing unnecessary transitions at the end of life by providing timely access to patient-centred care.[16] Community-based palliative care services have been associated with fewer hospital admissions in people with dementia in Australia[17] and the USA[18] However, people with dementia experience several barriers to access palliative care services.[19] Being the first point of contact, GPs play an important role providing end-of-life care, and contacts with GPs[20] and home health care[21] have been associated with lower risk of end-of-life admissions to hospital among older adults and people with dementia. It is not known how this relationship is affected by the frequency and length of contacts,[21] the level of continuity of care (CoC) experienced,[22] or whether palliative care needs are being identified by the GP.[23]

The aim of this study was (1) to describe primary care service utilization among individuals with dementia in the last year of life, and (2) explore associations between contacts, continuity of care with GPs, and palliative care needs identification with unplanned hospital admissions among people dying with dementia in the last 90 days of life.

Methods

Design and data sources

This is a nationwide population-based retrospective cohort study in England using the Clinical Practice Research Datalink (CPRD), linked with hospital records and mortality data from the Office for National Statistics (ONS). CPRD contains anonymised medical records from over 19 million people enrolled in 952 general practices across the UK.[24] People currently registered in CPRD primary care practices represent approximately 4.6% of the UK population.[25]

Population

Adults (>18 years and older) who died between 01/01/2009 and 31/12/2018, had a dementia diagnosis recorded in primary care or hospital records, and a 12-month before death registration period in a GP practice with continuous high-quality data based on CPRD quality checks.[24] Dementia diagnosis was identified from primary care records (using Read codes, standard clinical codes used in UK GP practices to record diagnosis and procedures),[26] and hospital records (using International Statistical Classification of Diseases and Related Health Problems 10 (ICD-10) codes), based on previous studies.[27] (Supplementary Box S1).

Outcome

The primary outcome was multiple unplanned admissions to hospital in the last 90 days of life (0 if no, 1 if yes), based on Gozalo et al. as either more than two unplanned admissions for any reason or more than one unplanned admission for respiratory, urinary tract infection, dehydration, or sepsis.[10] (Supplementary Box S2).

Explanatory variables

To describe primary care service utilization, we determined the number of participants' consultations with a GP in the last 12 months of life. We included face-to-face and telephone consultations regardless of where the consultation took place (practice, home or out-of-hours).

We defined an exposure period between months 12 and 4 before death (day 365 until day 91 before death). To account for the fact that participants in hospital cannot visit their GP, we calculated a rate of consultations with GPs per month dividing the total number of consultations with GPs by the number of days participants were in the community (excluding days in hospital) during the exposure period (Box 1).

We used the Consultation and Staff files provided by CPRD, which include an anonymised code identifying the physician who recorded each consultation, to calculate the Herfindahl-Hirschman index Continuity of Care Score (CoC) (Box 1).[28] This CoC score measures the extent to which

consultations during a certain period of time are with the same physician, and has a range from 0 to 1 (1 means all contacts the patient has in that period were with the same GP). Only contacts with GPs during the exposure period were considered.

Identification of palliative care needs was derived from the Palliative Care Register, an electronic register introduced in 2004 in England that aims to identify people in the GP practice who might benefit from a palliative care approach.[29] When patients are identified as having palliative care needs, their GP add a code in patients' clinical records that is then captured by the Palliative Care Register. We identified people with a relevant code at any point before the last 90 days of life, to recognise people who had been identified by their GPs as having palliative care need (Supplementary Table S7).[26, 30-32]

Co-variables

Factors associated with multiple hospital admissions in the last 90 days of life were examined based on previous research and theoretical models.[33, 34] Age at death was calculated using the year of death and year of birth. Gender and GP practice region were extracted from CPRD. We used the 2011 England and Wales rural-urban classification of the GP practice where participants were enrolled and the 2015 English Index of Multiple Deprivation quintiles at Lower Super Output Areas (LSOAs) level from the latest available participants's postcode of residence.

The underlying cause of death, place and date of death were identified from ONS. The underlying cause of death was grouped into ICD-10 block codes (Supplementary Table S2). We calculated the number of comorbidities (excluding dementia) using the count of chronic diseases from the Quality of Outcome Framework (QoF) Read codes rules (Supplementary Table S7).[26, 35] We used Read codes to identify whether participants had a record of living in a care home (nursing or residential care home) based on previous publications (Supplementary Table S1).[36]

Analysis

Changes in the annual proportion of participants with multiple hospital admissions in the last 90 days of life between 2009 and 2018 were explored using a scatter plot, with the proportion of multiple hospital admissions by year of death adjusted by age and sex. The mean (95% confidence interval) number of contacts with GPs by month before death was explored.

We used a multilevel Poisson regression with robust error variance and a random intercept for the region and participants' GP practice, to estimate the association between the rate of GP contacts per month, CoC score and identification of palliative care needs during the exposure period and multiple hospital admissions in the last 90 days of life. As CoC scores can only be calculated with at least two

contacts, participants with fewer than two contacts with GPs were excluded (2920 (8.7%)). Missing values for co-variables were small (<1%) and therefore excluded.

We performed a subgroup analysis to explore the influence of sociodemographic and illness-related factors on the association between the rate of GP contacts per month, CoC and identification of palliative care needs with the outcome.

We conducted three sensitivity analyses: (1) As the CoC score has been shown to be less stable when participants have fewer than 4 contacts, we performed the analysis excluding those participants; (2) We performed the same general multivariate model excluding CoC to include participants with fewer than 2 contacts with GPs; (3) we performed the analysis including people with at least one day of enrolment during the last year of life (n=57659). As an important proportion of people with less than 365 days of enrolment had fewer than 2 contacts with GPs, the COC score was excluded in this analysis.

All analysis were performed using Stata® version 16.1.

Results

Characteristics of the study sample

We identified 57659 people with dementia who died between 2009 and 2018 and were registered in a GP practice during the last year of life. After excluding 23945 people without a complete year of registration before death, 33714 participants were included in the analysis (Supplementary Figure S1). Demographic characteristics for people with and without a complete year of registration are described in Supplementary Table S4. The cohort had an average age at death of 86.6 years (SD 8.1), 64.1% were female, 21.5% lived in the least deprived quintile. 56.1% of the cohort had a code of living in a care home. The most common underlying cause of death was dementia (36.8%) followed by cerebrovascular disease (10.7%) and cancer (8.7%) (Table 1).

Of 33714 participants, 1894 (5.6%) had multiple hospital admissions in the last 90 days of life. This proportion increased from 4.9% (95% CI 4.2 to 5.6) in 2009 to 7.1% (95% CI 5.7 to 8.4) in 2018 (Figure 1). The mean CoC score in the cohort was 0.41 (SD 0.30). Participants with multiple hospital admissions in the last 90 days had lower CoC scores than those without these admissions (Table 2). 3169 (9.4%) participants were identified as having palliative care needs by a GP before the last 90 days of life, and they were less likely to have multiple hospital admissions in the last 90 days (Table 2).

Participants had on average 16.1 (SD 11.6) contacts with GPs in the last year of life, which increased closer to death, particularly in the last month of life (3.1 SD 2.9). Participants with multiple hospital

admissions had a higher mean number of contacts with GPs throughout the whole last year of life, except for the last month before death (Figure 2).

Multilevel adjusted model

In the adjusted model, participants with a higher rate of contacts with GPs per month were more likely to have multiple hospital admissions in the last 90 days of life. Participants with greater CoC scores and identification of palliative care needs were less likely to have multiple hospital admissions (Table 2). The subgroup analysis showed the positive association between the number of contacts with GPs and multiple hospital admissions in the last 90 days was significant for all groups for participants younger than 75, and for those whose underlying cause of death was dementia or cancer (Figure 3). Better CoC with GPs was associated with a lower risk of multiple hospital admissions mainly for participants older than 95, with more comorbidities, living in urban areas and not living in care homes. Identification of palliative care needs was associated with a lower risk of multiple admissions in older participants (>85 years old), those with no comorbidities, living in urban areas and in care homes, and for those whose underlying cause of death was dementia (Figure 3).

All sensitivity analysis performed showed similar results (Supplementary Table S5).

Discussion

Summary

In this large population-based cohort of people who died with dementia in England, we found more contacts with GPs was positively associated with multiple hospital admissions in the last 90 days of life, whereas CoC with GPs and identification of palliative care needs were negatively associated with these hospital admissions. CoC was particularly relevant for participants older than 95, those with more comorbidities, living in urban areas and not living in care homes. Identification of palliative care needs was particularly relevant in participants without comorbidities, and those living in urban areas and care homes.

Strength and limitations

This study uses a large nationwide population-based cohort linked with hospital and death certificates records. Participants with dementia were identified from primary and hospital care records, reducing the risk of missing people with incomplete records.

This study has some limitations. Restricting the sample to participants with a full year of enrolment in a GP practice is likely to exclude people who changed their GP practice due to deterioration or severe cognitive impairment.[37, 38] However, the sensitivity analysis including people with less than 365 days of enrolment showed similar results. We did not have information on the appropriateness

of admissions to hospital, quality of care or reasons for GP visits, which are likely to influence the risk of end-of-life admissions. We used Palliative Care QoF codes to identify people that have been recognised as having palliative care needs in primary care. However, these codes do not identify all people whose death is anticipated by the GP.[32]

The measure of CoC we used in this study does not capture the nature of the relationship between physicians and patients, or the quality of care received.[39, 40] While other measures of CoC exist, the Herfindahl-Hirschman CoC Score has been widely used in the literature and does not rely on the need to identify a usual provider.[28, 40-42]

Comparison with existing literature

Studies investigating the association between contacts with GPs and hospital use at the end of life show conflicting results. Contacts with GPs haven been positively associated with end-of-life hospital admissions among people with cancer in Canada[22] and older adults in Australia,[43] and negatively associated with end-of-life hospital admissions in USA in patients with congestive heart failure and chronic obstructive pulmonary disease.[20] In Chen et al,[21] people with dementia receiving home healthcare in Taiwan had higher risk of multiple hospital admissions in the last 90 days. However, this effect varied depending on the frequency and duration of home healthcare. Differences in results could also be explained by differences in health care systems,[44] and type of conditions. People with frequent hospital admissions are likely to have more GP contacts due to higher health care needs. However, it is possible that more GPs contacts might reflect poor coordination and integration between health care services. More research is needed to understand how interdisciplinary work between GPs and other community care services might have an impact on admissions to hospital in this population.[45, 46]

Two studies (both in cancer) explored the relationship between CoC and hospital admissions for people approaching the end-of-life in Canada[22] and England[47]) with similar findings to our study. CoC can increase trust between patients and doctors, increase adherence to long-term treatments, improve the quality of management, and reduce overaggressive treatment, in particular among people with multimorbidity and those living in the community.[48-51] Coc was low in our sample (mean CoC score 0.4). This is similar to findings from a study in older adults in the UK.[52] Indices that measure concentration of care, such as the CoC Score used in this study, are highly influenced by the number of contacts and type of professional considered (GP vs specialists), which could explain differences across studies.

Implications for research and/or practice

Despite the evidence for the potential benefit of CoC,[53] the proportion of patients who were able to see their preferred GP has declined by 9% between 2012 and 2017 in England.[54] Strategies such as assigning a key worker,[33] assigning patients to small multidisciplinary teams within a practice, enhancing the role of receptionists to support continuity, and prioritising continuity for patients who may benefit the most, have been recommended to improve the level of CoC,[55] and might help prevent unnecessary admissions to hospital in older people with dementia and multimorbidity living at home.

Our finding suggests that identifying people who might benefit from a palliative care approach could help to reduce unnecessary end-of-life transitions to hospital. These findings are consistent with results from a previous study in a London population.[23] However, recognising when people with dementia are approaching the end of life is challenging, and GPs have reported barriers to doing so, such as lack of knowledge and training.[56, 57] Screening tools such as the Supportive and Palliative Care Indicators Tool (SPICT) or the Electronic Frailty Index (eFI) developed in the UK for primary care settings, [58, 59] and the IPOS-Dem developed specially for people with dementia,[60, 61] might help GPs flag people with high risk of deteriorating and dying, assess patients' needs and identify those who might benefit from a palliative care approach.

Conclusions

Multiple hospital admissions in the last 90 days of life are increasing among people dying with dementia in England. Our findings suggest that improving the level of continuity of primary care and identification of palliative care needs among people with dementia may help reduce burdensome transitions into hospital near the end of life.

Additional information

Funding

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Ethics committee approval

The CPRD has broad National Research Ethics Service Committee (NRES) ethics approval for purely observational research. No further ethical approval was required for the analysis of the data as this study used anonymised data only.

Conflicts of interest

The Authors declare that there is no conflict of interest.

Data sharing

The data that support the findings of this study are available from the Clinical Practice Research Datalink (CPRD). Access to CPRD data is subject to protocol approval by an Independent Scientific Advisory Committee (ISAC). The protocol of this study was approved by the ISAC in April 2021 (Protocol 20_031)

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Box 1. Formulas for calculating Rate GP contacts and continuity of care score

Rate GP contacts per month:

$$= \frac{\text{number of contacts with a GP between months 12 to 4 before death}}{(271 - \text{ number days in hospital between months 12 to 4 before death})} \text{ x } 30$$

Continuity of care score:

$$CoC = \frac{(\sum n_i^2 - N)}{N(N-1)}$$

n_i = the number of contacts the patient has with a GP during the exposure period (months 12 and 4 before death)
N= the total number of GP contacts during exposure period.

Table 1. Characteristics of participants by multiple hospital admissions in the last 90 days.

	Total		Multiple unplanned hospital admissions last 90 days			
			No		Yes	
	Freq.	%	Freq.	%	Freq.	%
	33714		31820	94.4	1894	5.6
Age (Mean)	86.56	(SD 8.07)	86.69	(SD 8.01)	84.67	(SD 8.79)
Gender						
Male	12091	35.9	11171	35.1	920	48.6
Female	21623	64.1	20649	64.9	974	51.4
IMD quintiles						
(Least deprived) 1	7260	21.5	6906	21.7	354	18.7
2	7451	22.1	7062	22.2	389	20.5
3	7837	23.3	7459	23.5	378	20.0
4	5895	17.5	5549	17.5	346	18.3
5	5258	15.6	4831	15.2	427	22.5
Missing	13					
Lived in care home						
No	14818	44.0	13816	43.4	1002	52.9
Yes	18896	56.1	18004	56.6	892	47.1
Rural						
Urban	28921	85.8	27192	85.5	1729	91.3
Rural	4793	14.2	4628	14.5	165	8.7
Region						
North East	703	2.1	666	2.1	37	2.0
North West	5947	17.6	5510	17.3	437	23.1
Yorkshire & The Humber	1047	3.1	981	3.1	66	3.5
East Midlands	364	1.1	342	1.1	22	1.2
West Midlands	4028	12.0	3785	11.9	243	12.8
East of England	2755	8.2	2618	8.2	137	7.2
South West	4855	14.4	4678	14.7	177	9.4
South Central	5311	15.8	5121	16.1	190	10.0
London	3386	10.0	3107	9.8	279	14.7
South East Coast	5318	15.8	5012	15.8	306	16.2
Cause of death						
Dementia	12404	36.8	11917	37.5	487	25.7
Cancer	2926	8.7	2731	8.6	195	10.3
Cerebrovascular disease	3615	10.7	3429	10.8	186	9.8
Ischaemic heart disease	2510	7.5	2363	7.4	147	7.8
Influenza and pneumonia	1800	5.3	1657	5.2	143	7.6
Chronic Pulmonary disease	1148	3.4	1003	3.2	145	7.7
Chronic heart disease	1160	3.4	1087	3.4	73	3.9
Parkinson	831	2.5	801	2.5	30	1.6
Senility	750	2.2	737	2.3	13	0.7
Other	6565	19.5	6090	19.1	475	25.1
Missing	5					
Number of QoF comorbidities (Mean)	2.23	(SD 1.60)	2.20	(SD 1.59)	2.72	(SD 1.69)
Place of death						
No home	30,376	90.10%	28,577	89.81%	1,799	94.98%
Home	3,338	9.90%	3,243	10.19%	95	5.02%

QoF: Quality of life Framework, IMD: index of multiple deprivation

Figure 1. Age and sex adjusted proportion of decedents who experienced multiple hospital admissions in the last 90 days of life by year of death.
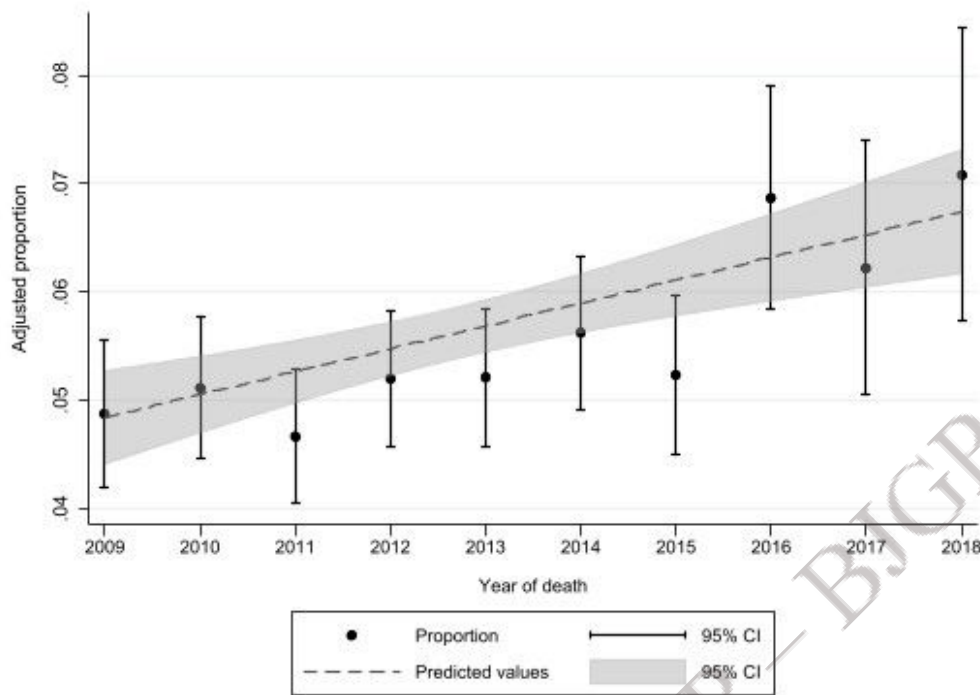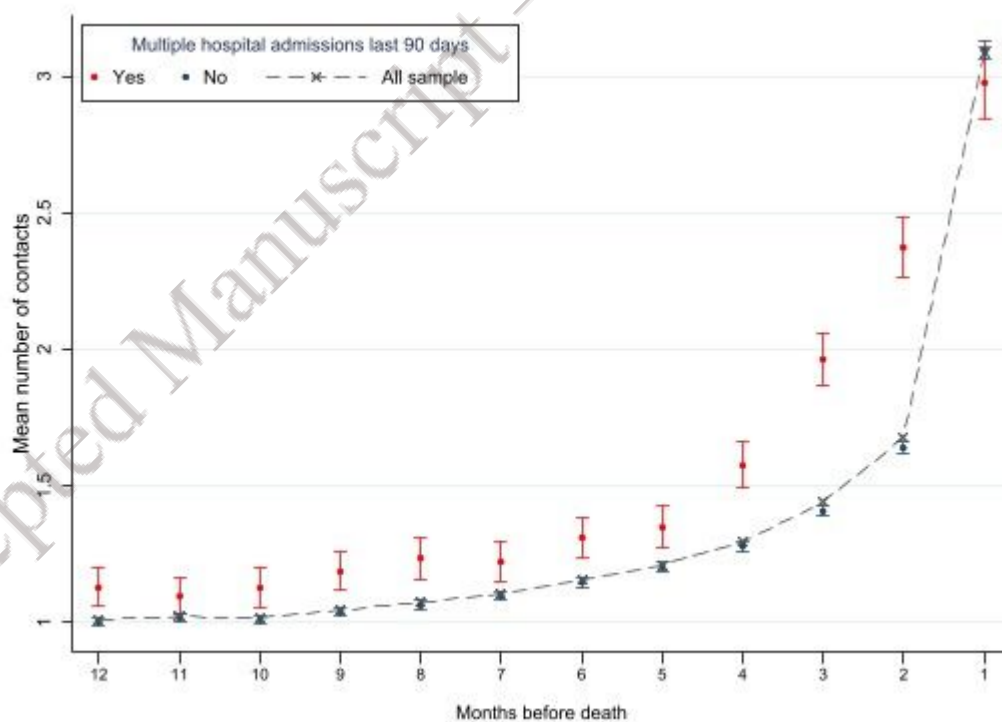

Figure 2. GP contacts for participants with and without multiple hospital admissions by month before death.

The figure shows the mean number of contacts with GPs in the last 12 months of life for participants with dementia with and without multiple hospital admissions in the last 90 days by month before death.

Table 2. Association between GP contacts, CoC score, identification of palliative care needs and multiple hospital admissions.

	Multiple hospital admissions in the last 90 days						IRR*	95% CI	p-value
	No n=31820			Yes n=1894					
	N° events	N° days in community	IR x 30 days	N° events	N° days in community	IR x 30 days			
GP contact rate (12-4 months before death)	313501	8395512	1.12	21259	488090	1.31	1.08	(1.05-1.11)	<0.001
	Mean	**SD**		**Mean**	**SD**				
Continuity of care score (12-4 months before death)	0.41	0.30		0.38	0.28		0.79	(0.68-0.92)	0.003
	Freq	**%**		**Freq**	**%**				
Palliative care QoF any time before last 90 days									
No	28782	90.5		1763	93.1				
Yes	3038	9.6		131	6.9		0.66	(0.56-0.78)	<0.001

QOF: Quality of life Framework; IR: incidence rate; IRR: incidence risk ratio; SD: standard deviation.

*Multilevel Poisson model with a random intercept for Region and GP practice, adjusted by age, number of QoF comorbidities, gender, Index of Multiple Deprivation, rurality, living in a care home, cause of death, and year of death. The model includes only participants with at least two contacts with the GP during the exposure period. The full model is available in supplementary material.

Figure 3. Subgroup analysis.
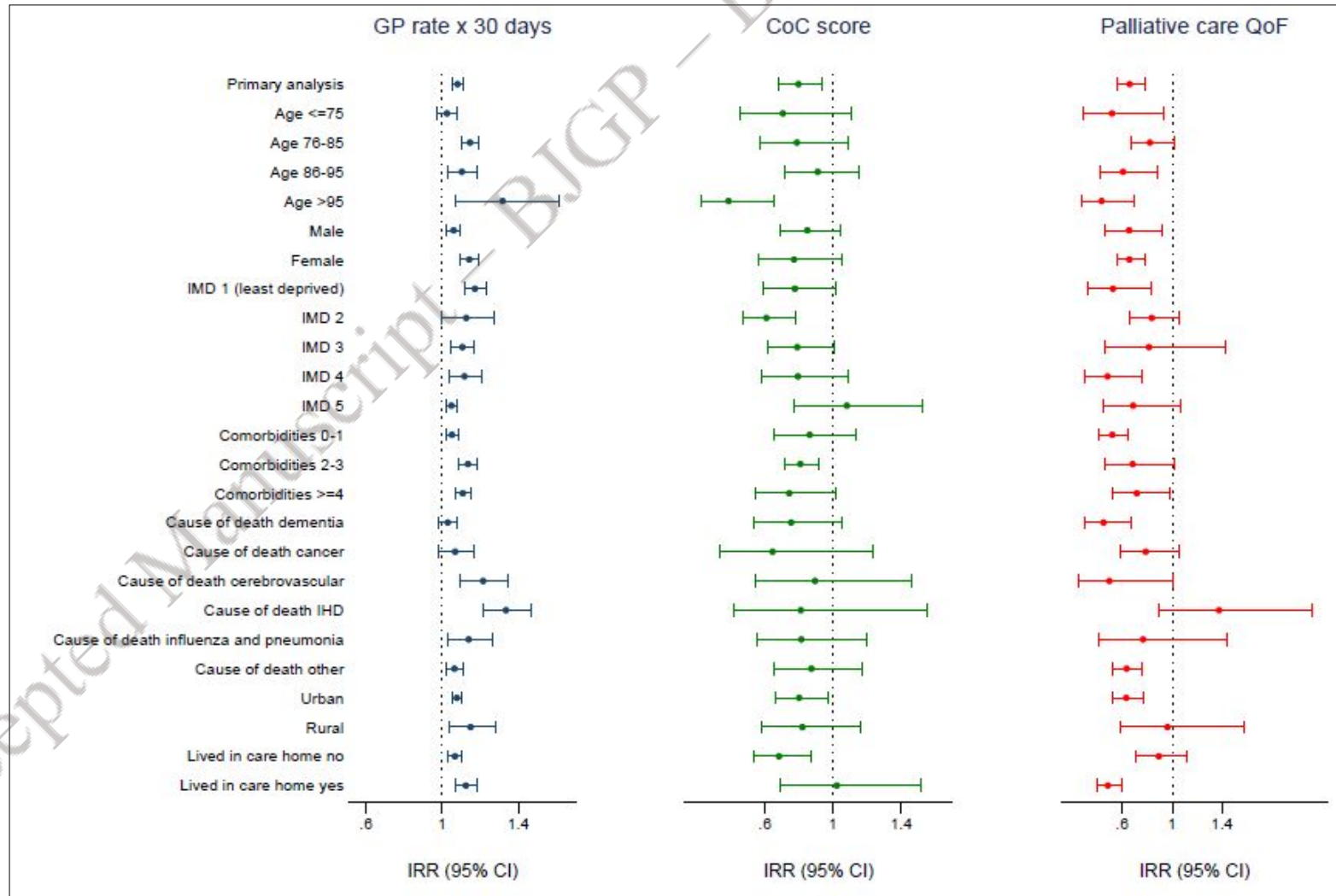
The figure shows results from the subgroup analyses exploring the influence of sociodemographic and illness-related factors in the association between the rate of GP contacts per month, continuity of care score and identification of palliative care needs before the last 90 days of life with multiple hospital admissions in the last 90 days of life (primary analysis). The Incidence risk ratio (IRR) represents the risk of multiple hospital admissions for the monthly rate of GP contacts, level of continuity of care and identification of palliative care needs before the last 90 days of life respectively. All models are adjusted by age, number of comorbidities, IMD quintile, underlying cause of death, rurality, gender, living in care homes, and year of death, excluding the variable used for the subgroup analysis, and include a random intercept for region and GP practice.