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Out of hours primary care contacts by patients at the end of life: a population based study.

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Abstract

Objectives: Out of hours (OOH) primary care services are a key element of community care at the end of life, yet there have been no previous attempts to describe the scope of this activity. We aimed to establish the proportion of Oxfordshire patients who were seen by the Out Of Hours service within the last 30 days of life and whether they were documented as in a palliative phase of care.

Design Population based study linking a database of patient contacts with OOH primary care with the register of all deaths within Oxfordshire (600000 population) during 13 months.

Setting Oxfordshire

Participants Between 1/12/14 and 30/11/2015 there were 102,877 OOH contacts made by 67,943 patients with the OOH service.

Main outcome measures Proportion of patients dying in the Oxfordshire population who were seen by the Out Of Hours service within the last 30 days of life. Demographic and clinical features of these contacts.

Results 29.5% of all population deaths were seen by the OOH service in the last 30 days of life. Among the 1530 patients seen, patients whose palliative phase was documented (n=577, 36.4%) were slightly younger (median age = 83.5 vs 85.2 years, p<0.001) and were seen closer to death (median days to death = 2 v 8, p<0.001). More were assessed at home (59.8% vs 51.9%, p<0.001) and less were admitted to hospital (2.7% vs 18.0%, p<0.001).

Conclusions OOH services see around one third of all patients who die in a population. Most patients at the end of life are not documented as palliative by OOH services and are less likely to receive ongoing care at home.

Strengths and Limitations of this study

- This is the first study to use data linkage with death records to describe the true population at the end of life who contact the OOH service.
- The study highlights both the importance of the OOH primary care service in end of life care and the significant limitations of medical records studies which have used clinical coding of palliative care as a proxy for end of life contacts
- Our understanding of the proportion of these deaths which were palliative and the causes of death relied on the accuracy of clinical coding
- Our study focused on a single area of the UK due to restriction in access to OOH provider medical records

Introduction

The provision of primary care services outside core contracted hours is fundamental to the operation of the NHS.[1] In 2013-14, out of hours GP services (OOH) in England handled approximately 5.8 million cases, 3.3 million of which were face to face consultations, including 800,000 home visits.[2] For the majority of patients OOH primary care is provided by a clinician who does not know them, often with limited access to their medical record.[3]

In January 2015 the top research priority identified by the Palliative and end of life care Priority Setting Partnership was the provision of palliative care outside of working hours to help patients stay in their place of choice by managing crises.[4] Given that the majority of people with terminal illness do not wish to die in a hospital[5], OOH primary care services must be viewed as an integral part of end of life care provision.

Our current understanding of the true extent of end of life care provided by the OOH service is limited. OOH services do not routinely receive feedback on patient deaths following contact with the service. We previously analysed an OOH service database[6] and learned that patients whose needs were coded as palliative contacted the OOH service predominantly during weekend daytime periods, and that over a third had multiple contacts with the service. However, the study was limited because we were not able to identify all patients who had died and had contacted the service, thus underestimating the true proportion of patients with end of life care needs.

In order to understand how OOH care can best be provided at the end of life we need to understand the true extent of this workload, its nature, and whether there are differences between patients who appear to be recognised as palliative by clinicians and those who are not. This study used data linkage to identify people who died in Oxfordshire over the course of a year who had contact with the OOH services in the 30 days before death and the clinical care that they received from the OOH service.

Methods

The Oxfordshire OOH service provides care to a population of over 600,000 people from 18:30pm – 08:00am on weekdays and 24 hour cover on weekends and bank holidays. Access to the service is via the NHS 111 telephone advice line, where trained call handlers use the NHS Pathways algorithm to direct patients to the most appropriate service for their needs. Patients directed by 111 to the OOH service will receive an initial telephone consultation with an OOH clinician which may then lead to a

base visit (patient comes to the OOH surgery to be seen), home visit or the case being passed to another care provider (such as 'hospital at home'). Patients can also be booked directly by 111 to an OOH base visit.

A database of all patient contacts with the Oxfordshire Out of Hours (OOH) service over 1 year from 01.12.14 to 30.11.2015 was created from the OOH Electronic Record System used by clinicians (Adastra).

Mortality data for Oxfordshire (population 600,000) over 13 months (1.12.14-31.12.15) was obtained via NHS Digital/Office of National Statistics, with Section 251 approval from the Confidentiality Advisory Group. This was linked by NHS number with Oxfordshire OOH service care records and was used to identify people who had contact with the OOH service in the 30 days prior to death. All patient identifiers were removed on entry to the database. Any contact without an NHS number was removed from the database, as repeat visits could not be assessed, as were those with a duplicate case ID. Contacts that were seen after death were also removed. Demographic data consisted of age, sex and Index of Multiple Deprivation score (available for 79% of contacts).[7] Service data included final contact type, outcome, date, clinical codes assigned and prescriptions issued. Mortality data included the date of death and all assigned ICD-10[8] causes of death.

Timings of calls were classified as evening 18:30-23:59, overnight 00:00-07:59 and daytime (i.e. weekends and bank holidays) 08:00-18:29. The number of days difference between contact and death was calculated using calendar days beginning at midnight. Weekend period was classified as 18:30 Friday until 08:00 Monday.

Those who died were also classified according to whether they had been documented by the service as palliative or not. We defined palliative patients as those who, at any contact with the OOH service in the study period, had been assigned a clinical code relating to palliative care, been referred to a hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication. This group was compared with all other patients who died within 30d of contact.

Validation

In order to validate the clinical codes applied by the OOH clinicians we estimated, based on previous coding validity studies[9] that analysis of 230 records would be required to establish the coding validity with a confidence level of 90% and 5% margin of error. A random selection of 230 records was obtained using SPSS, and the clinical code was compared by two authors (SG, HH) to the conclusion

drawn by the clinician in the medical notes. The PPV of the clinical code for medical diagnosis or conclusion was 92.6%.

Statistical analysis

Demographic details and details concerning the cause of death were compared at a patient level, so that each patient was only considered once in the analysis. By contrast, the OOH contact and outcome were compared at an OOH contact level. Statistical analysis was performed using SPSS Version 22. T tests were used when comparing means, z tests when comparing proportions and Mann Witney U test when comparing medians. Logistic regression was performed to test associations for binary outcomes. This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

Results

Between 1/12/2014 -30/11/2015 there were 102,877 contacts, by 67,943 patients, with the Oxfordshire OOH service. In the 13 month period between 1/12/14 – 31/12/15, 5193 people died in Oxfordshire. Of the people who died, 1530 (29.5%) had contact with the OOH service in the 30 days prior to their death. These patients made 2661 contacts with the OOH service in the 30d prior to their death, accounting for 2.57% of all contacts to the service over the 12 month study period. A further 791 contacts (with 752 patients) occurred *after* death, equating to 14.5% of all deaths and 0.76% of all contacts to the service. Contacts after death were excluded from further analyses.

Of those patients who had contact with the OOH service in the 30d prior to death, 381 (24.9%) made a contact in the last day of life (Figure 1). There was a median of 5 (IQR 1.75 – 13) days between final OOH contact and death and the median number of contacts with the OOH service in the 30d prior to death was 1 (IQR 1 – 2). A similar proportion of deaths occurred on each day of the week (figure 2)

Tables 1 and 2 compare patients and patient contact features of those who died within 30 days of death with those who were alive at 30 days after initial OOH consultation. Patients who died were were older, less deprived and more likely to be male. Patient contacts were more frequently in their own home and more likely to have their care escalated to an alternative provider (hospital, hospice, community care provider).

For those patients who died within 30 days the most commonly assigned clinical codes were palliative (27.3% of all codes assigned), advice (8.8%), medication requests (7.1%), lower respiratory tract infection (LRTI) (5.5%) or urinary tract infection (UTI) (4.2%) codes. By comparison, Ear, Nose and Throat disorder (ENT) (13.5%), UTI (6.0%), musculoskeletal disease (MSK) (5.3%), upper respiratory tract infection (URTI) (4.9%), and medication requests (4.2%) were the commonest codes in those alive at 30 days after index assessment (supplementary tables 1 and 2)

Acute events were the cause of death in 25% of patients. The commonest codes were types of cancer (45.6%) followed by cardiac disease (34.8%), LRTI (25.2%), dementia (23.9%), age related debility and other respiratory disease (both 15.2%) (see table 4 for full list).

Comparison between palliative patients and patients dying within 30 days not documented as palliative.

Patients who had contact with the OOH service in the 30 days prior to death were categorised into those who had been documented by the service as palliative (any palliative code assigned to record, hospice referral, or appropriate subcutaneous medication prescribed at any time), and those who had not.

557 patients (36.4%) were documented as palliative, and had 1310 contacts with the OOH service in the 30 days prior to death. By contrast, 973 patients (63.6%) were not documented as palliative, accounting for 1351 contacts.

Patients documented as palliative were younger than those not documented (median 83.5 years (IQR 74.1 – 89.6) vs 85.2years (IQR 78.3 – 91.1) ($p<0.001$, $z=4.45$), an association which was maintained after adjusting for sex and deprivation in multivariable logistic regression (OR 0.98, $p<0.001$, 95% CI 0.97-0.99).

There were clear differences in the patterns of service use, depending on documentation of palliative phase of care. Patients documented as palliative were seen more frequently in the 30d prior to death (median 3 contacts, IQR 2-4, v median 2 contacts, IQR 1-3 $z = -12.813$ $p<0.001$) , and their final contact with the service was closer to the point of death (median number of days between final contact and death 2 (IQR 1-6), days v 8 (IQR 3-17) days $z = -15.335$ ($p<0.001$), with 42.2% (v 15.1%) being seen on the day of death or day prior to death.

Patients documented as palliative presented less frequently at the weekend (67.2% v 70.4%; $z=-1.79$, $p=0.037$), and more frequently overnight (27%, vs 18.3%,$z=5.391$, $p<0.001$). They were more likely to

be assessed at a home visit (59.8% v 51.9%; z=4.094, p<0.001) and less likely to be managed solely through telephone contact (43.2% vs 36.6%, z=-3.508, p=0.002).

The two groups of patients differed in the outcomes of contacts with the OOH service. Patients documented as palliative were less likely to be admitted to hospital following their assessment (2.7% vs 18.0% respectively, z=-8.091, p<0.001), but more likely to be referred for community input (12.7% vs 2.3%, z=10.221, p<0.001) or require no further follow up (40.8% vs 35.7%, z=2.7, p=0.0035) (Table 3).

In addition to palliative codes, the most common clinical codes assigned in those patients documented as palliative were medication related (7.4%), advice (6.35%), LRTI (2.8%), nausea and vomiting (2.0%) and catheter care (1.6%). In those patients not documented as palliative, a wider range of clinical codes were applied, the commonest were advice (10.8%), LRTI (8.4%), UTI (6.9%), medication related (6.2%) and shortness of breath (4.2%) (supplementary tables 3 and 4).

Causes of death in both groups are detailed in table 4. The highest proportion of deaths was due to cancer in the group documented as palliative (70.7%); over twice that in those not documented as palliative (31.2%). There were similar proportions of patients with dementia as cause of death. Conversely, infections, myocardial infarction, pulmonary embolism, gastroenterological and endocrinological diseases were over twice as frequently assigned to patients in the group not documented as palliative. Causes of death which would be considered acute events (acute kidney injury, myocardial infarction, pulmonary embolism, fracture, fall, trauma, stroke and sepsis) were applied to 18.1% of patients documented as palliative and 29.3% of those not documented as palliative.

Discussion

OOH GP services provide end of life care to almost a third of people who die in a population, frequently very close to death. This places OOH GP services at the forefront of end of life care provision. Patients at the end of life are more likely to contact the service overnight, likely in part due to the reduction in availability of other services at these times. Death administration contributes significantly to the workload of the OOH service, being required for 14.5% of all deaths. Just 0.4% of all contacts occurring within the 30 days prior to death result in a hospice admission.

Only 36.4% of patients contacting the service at the end of life were documented as palliative, hence studies relying on clinical coding of patient contacts as palliative will significantly under report the burden on the service. A large number of contacts in the 30 days prior to death result in a home visit irrespective of documentation of a palliative phase of care, reflecting significant frailty within this patient group. Patients not documented as palliative had a much higher rate of acute hospital admission, suggesting that initial management strategy is based on addressing an acute presenting illness syndrome with hospital based care in this group.

The only study which has used a similar methodology to explore OOH service use at the end of life reported a similarly high proportion (25%) of deceased patients contacting a Norwegian OOH service in the 4 weeks before death, with a much higher proportion (37%) referred to hospital at their OOH contact.[10]

Strengths and Limitations

This is the first study to accurately report the proportion of patients who die shortly after contact with OOH primary care by linking UK OOH records with mortality data. However, there are several limitations to our analysis. By excluding deaths of patients living outside Oxfordshire we may have underestimated demands on the service. Our analysis was also limited to contacts within 30 days of death, however the majority of contacts were within 7 days of death, suggesting that this has not significantly limited our conclusions

In order to explore whether the service recognised the patient contact as palliative we relied on OOH clinicians assigning a palliative code to the patients record or a documenting an action only relevant to palliative care (prescribing subcutaneous medication or hospice referral). Some patients who were recognised by the service as needing end of life care may have been misclassified in this analysis. Similarly we relied on the accuracy of cause of death as recorded by either the regular general practitioner or hospital clinician. It is possible that acute events could be under reported in death certificates if active malignancy is present.

Implications

The OOH service is making a significant contribution to end of life care. Despite a majority of patients with terminal illness wishing to die at home, only a minority currently achieve this.[11] Enabling good deaths in the community is therefore a key component of OOH primary care

provision. Ensuring that the OOH service is fit for this purpose in terms of staff skill mix and resource is imperative.

Two thirds of patients who died within 30 days of OOH contact were not documented as being in a palliative phase of care. There will be patients for whom an acute life threatening syndrome has led to an OOH contact. The percentage of deaths which were due to acute events was 25% overall, in line with national estimates[12], and relatively higher in the group not documented as palliative (29.3%). In addition, clinicians may recognise patients to be at the end of life, but choose to use more immediately relevant clinical codes for the contact or be reluctant to use palliative codes for patients who do not have cancer. Furthermore, there may be patients at the end of life where it is simply not recognised in the setting of multiple morbidity and frailty.

A greater number of acute, gastrointestinal, infection and cardiac codes were applied to patients who were not documented as palliative. Gastrointestinal conditions in particular have been highlighted previously as challenging to diagnose in prehospital urgent care settings.[13,14] Evolving OOH care services to include a greater range of POC blood and imaging diagnostics and tailored risk scores could offer clinicians support in triaging and managing these difficult presentations.

Reviews of deaths are standard practice in acute trusts and are viewed as integral to learning and service improvement and in hours GPs are routinely informed of deaths of patients in their care. However, there is no routine mechanism to feedback to clinicians working in OOH services when deaths occur after contact. This deprives clinicians of the opportunity for valuable reflection and learning and services of the opportunity for improvement.[15] It is particularly relevant in light of the recent CQC call [16] to end missed opportunities to learn from patient deaths. Following the Mazars report[17], there is an increased focus on more robust systems to learn from deaths of patients following contact with NHS trust services. This study may help OOH services prioritise deaths for mortality review to maximise learning.

Conclusion

The contribution of OOH primary care services to patients at the end of life has previously been under-researched and underestimated. This study demonstrates that almost a third of people who

die have contact with an OOH service in the preceding 30 days. Further work to understand the how OOH primary care can best meet the needs of patients at the end of life is required.

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Data sharing

No additional data available

Authors' contributions.

GH and DL conceived the study. RF developed the protocol, gained study permissions and developed the databases. RB DL and GH analysed the data. HH and SG validated the dataset. RB and GH drafted the manuscript and all authors contributed to interpretation of results and critical revision of the manuscript.

Competing interest statements

All authors have completed the *Unified Competing Interest form* (available on request from the corresponding author) and declare: no support from any organisation for the submitted work [or describe if any]; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Ethics committee approval

This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

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Figures

Figure 1 Number of days between final OOH contact and death expressed as cumulative percentage

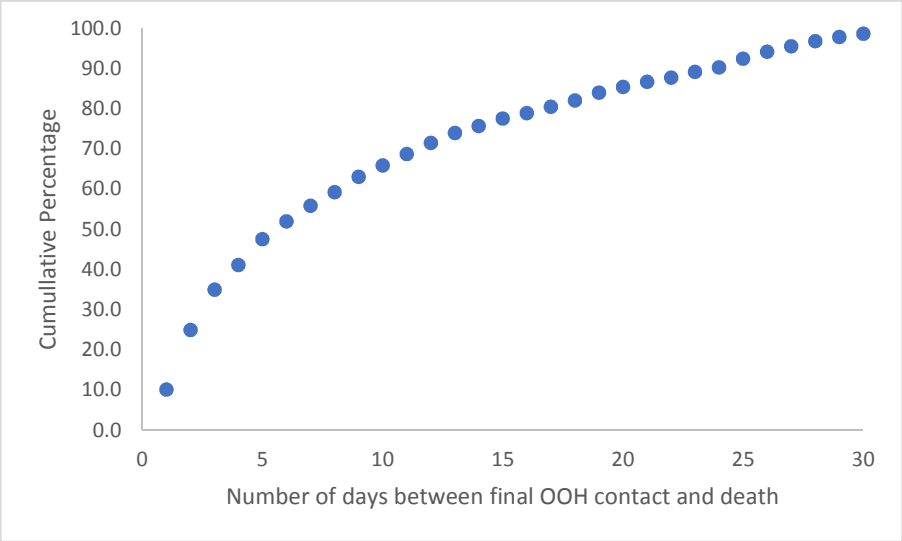
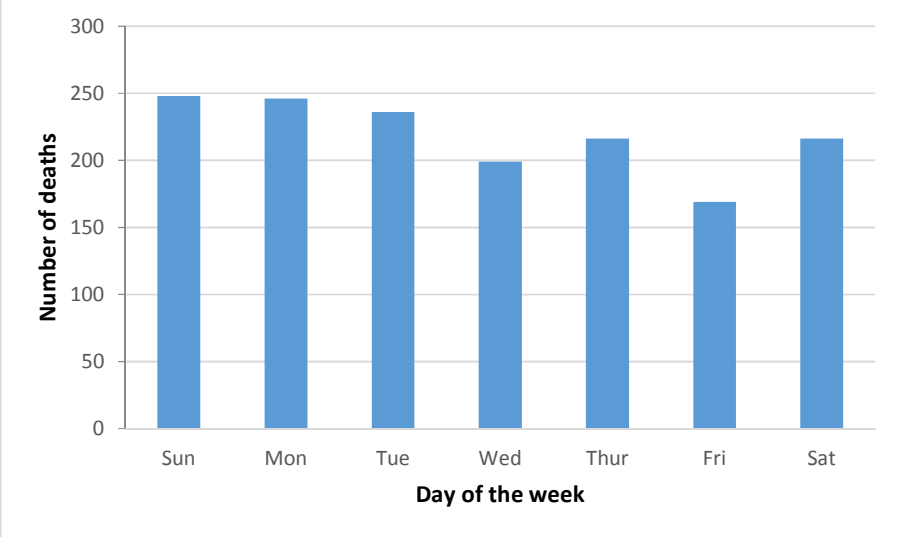


Figure 2 Number of deaths occurring on each day of the week



Tables

Table 1: Characteristics of patients contacting the service within 30 days of death compared to all other patients

	Patients within 30d of death (n = 1530)	Patients not within 30d of death (n = 66413)
Age (median, IQR)	84.9 (77.0 – 90.6) yrs	33.3 (12.2-- 59.2) yrs
Gender (percentage, 95%CI)	44.3% (41.8 – 46.8)	41.6% (41.2 – 42.0)
IMD* score (mean, sd)	12.00 (9.30)	13.13 (9.67)

*Index of multiple deprivation

Table 2: Characteristics of patient contacts with the service within 30 days of death compared to all other contacts

	Contacts within 30d of death (n = 2661)	Contacts not within 30d of death (n = 100216)
Contact type (percentage (95%CI))		
Home visit	55.8% (53.9 – 57.7)	9.7% (9.5 – 9.9)
Base assessment	4.2% (3.4 – 5.0)	55.8% (55.5 – 56.1)
Telephone contact only	39.9% (38.0 – 41.8)	34.3% (34.0 – 34.6)
Time of contact (percentage (95%CI))		
Overnight 00:00-07:59	22.6% (21.0 – 24.2)	15.5% (15.3 – 15.7)
Evening 18:30-23:59	29.4% (27.7 – 31.1)	37.8% (37.5 – 38.1)
Daytime 08:00-18:29	48.0% (46.1 – 49.9)	46.7% (46.4 – 47.0)
Outcome of the contact (percentage (95%CI))		
Acute admission (hospital, A&E, Emergency Multidiscplinary Unit)	10.5% (9.3 – 11.7)	7.43% (7.3 – 3.6)
Admission to hospice	0.4% (0.1 – 0.6)	0.03% (0.03 – 0.03)
Community input (Hospital at home, community nursing, social services, minor injury unit, mental health team)	7.4% (6.4 – 8.4)	1.2% (1.1 – 1.3)
Did not attend/unable to contact/left before treatment	0.3% (0.1 – 0.6)	1.4% (1.3 – 1.5)
GP Follow-up	38.2% (36.3 – 40.0)	36.8% (36.5 – 37.1)
No Follow-up	38.3% (36.3 – 40.0)	49.3% (49.0 – 49.6)
Other	5.1% (4.3 – 5.9)	3.8% (3.7 – 4.0)

Table 3: Outcomes of contacts with patients documented palliative v those not documented palliative

Outcome of contact	Documented as palliative		Not documented as palliative	
	Frequency	Percentage of contacts	Frequency	Percentage of contacts
Acute admission (hospital, A&E, EMU)	35	2.7%	243	18.0%
Admission to hospice	10	0.8%	0	0.0%
Community input (H@H, comm nursing, SS, MIU)	166	12.7%	31	2.3%
Unable to contact	2	0.2%	7	0.5%
GP FU	493	37.6%	522	38.6%
No FU	534	40.8%	482	35.7%
Other (OP clinic, passed to another provider)	68	5.2%	63	4.7%
Outcome missing	2	0.2%	3	0.2%
Total	1310	100.0%	1351	100.0%

Table 4: All assigned Causes of death by documented palliative / not and total

	Documented as palliative		Not documented as palliative		Total	
	frequency	percentage of patients	frequency	percentage of patients	frequency	percentage of patients
Malignancy	394	70.7	304	31.2	698	45.6
Cardiac disease excluding myocardial infarction	137	24.6	396	40.7	533	34.8
Acute lower respiratory infection	87	15.6	298	30.6	385	25.2
Dementia	121	21.7	244	25.1	365	23.9
Age-related physical debility	96	17.2	136	14.0	232	15.2
Respiratory disease	57	10.2	175	18.0	232	15.2
Stroke (haemorrhage or infarction)	56	10.1	124	12.7	180	11.8
Gastrointestinal disease	20	3.6	128	13.2	148	9.7
Type 2 diabetes mellitus without complications	39	7.0	105	10.8	144	9.4
Hypertension	37	6.6	104	10.7	141	9.2
Kidney disease	40	7.2	99	10.2	139	9.1
Peripheral vascular disease	21	3.8	51	5.2	72	4.7
Neurological disease	21	3.8	44	4.5	65	4.2
Urinary tract infection	6	1.1	53	5.4	59	3.9
Rheumatological disease	20	3.6	39	4.0	59	3.9
Other	13	2.3	40	4.1	53	3.5
Complication of procedure / surgery	14	2.5	32	3.3	46	3.0
Sepsis	8	1.4	37	3.8	45	2.9
Endocrinological disease	6	1.1	35	3.6	41	2.7
Parkinson's disease	12	2.2	28	2.9	40	2.6
Acute kidney failure	6	1.1	34	3.5	40	2.6
Acute myocardial infarction	8	1.4	31	3.2	39	2.5
Fracture	14	2.5	25	2.6	39	2.5
Pulmonary embolism	6	1.1	24	2.5	30	2.0
Infection (excluding LRTI & UTI)	4	0.7	25	2.6	29	1.9
Psychiatric	6	1.1	14	1.4	20	1.3
Non-malignant haematological	4	0.7	12	1.2	16	1.0
Traumatic	2	0.4	6	0.6	8	0.5
Fall	2	0.4	2	0.2	4	0.3
Drug related	0	0.0	4	0.4	4	0.3

Supplementary tables

Table 1: most commonly assigned clinical codes (>1%) to contacts in 30d prior to death

Clinical Code (grouped)	Frequency	% of all codes assigned.
Palliative	957	27.27%
Advice/reassurance	307	8.75%
Medication request/prescribed	248	7.07%
LRTI	194	5.53%
UTI	148	4.22%
SOB	95	2.71%
N&V	79	2.25%
Procedure	73	2.08%
Other Respiratory illness or symptom	73	2.08%
Catheter care	66	1.88%
Confusion/reduced GCS	55	1.57%
Pain	53	1.51%
Abdominal Pain	47	1.34%
Other	47	1.34%
Condition or symptom NOS	46	1.31%
Abnormal bloods	45	1.28%
Wound care	44	1.25%
Collapse or Fall	39	1.11%
Emergency treatment	36	1.03%
Agitation	35	1.00%
Cancer	35	1.00%

Table 2: Most commonly assigned clinical codes (>1%) to contacts alive at 30 days after OOH contact

Clinical code (grouped)	Frequency	% of all codes assigned
ENT symptom or condition	10507	13.49%
UTI	7305	6.00%
MSK disease	6443	5.30%
URTI	5909	4.86%
Medication request/prescribed	5141	4.23%
Advice/reassurance	4866	4.00%
Abdominal pain	4845	3.98%
Viral illness	4658	3.83%
Other respiratory symptoms or illness	4324	3.55%
Diagnosis not made	3733	3.07%
Skin infection	3470	2.85%
LRTI	3260	2.68%
Skin condition	3043	2.50%
Wound care	2708	2.23%
Gastroenteritis	2634	2.16%
Fever	2564	2.11%
Failed encounter/DNA	2405	1.98%
Mental health symptom/condition	2278	1.87%
N&V	2271	1.87%
Neurological condition	2158	1.77%
Accidental injury	2105	1.73%
GI disease or symptom	1995	1.64%
Catheter care	1950	1.60%
Eye problem	1876	1.54%
Oral disease	1752	1.44%
Urological disorder	1673	1.38%
Pregnancy, antenatal care or pregnancy complication	1376	1.13%
Diarrhoea	1314	1.08%
Chest pain/IHD	1281	1.05%

Table 3: Clinical codes most commonly assigned to contacts with patients not documented as palliative (codes accounting for >1% of all codes assigned.)

Clinical code (grouped)	Frequency	% of all codes
Advice	191	10.82%
LRTI	148	8.39%
UTI	121	6.86%
Medication request/prescribed	110	6.23%
SOB	74	4.19%
N&V	48	2.72%
Pain	39	2.21%
Catheter care	38	2.15%
Abdominal Pain	37	2.10%
Procedure	37	2.10%
Confusion	36	2.04%
Abnormal bloods	35	1.98%
Respiratory illness	32	1.81%
MSK disease	32	1.81%
Other	31	1.76%
Wound care	29	1.64%
Ill defined condition	27	1.53%
COPD	26	1.47%
Emergency treatment	25	1.42%
Fall	24	1.36%
Chest pain	22	1.25%
CVA	22	1.25%
Failed encounter	21	1.19%
Referral	20	1.13%
Dehydration	19	1.08%
Skin infection	19	1.08%
Unwell	18	1.02%
Sepsis	18	1.02%
GI bleed	18	1.02%

Table 4: Clinical codes (grouped) most commonly assigned to contacts with patients coded as palliative (i.e. codes accounting for >1% of all codes assigned.)

Documented as palliative		
Clinical code (grouped)	Frequency	% of all codes assigned
Palliative	1134	54.15%
Medication request/prescribed	155	7.40%
Advice	133	6.35%
LRTI	59	2.82%
N&V	42	2.01%
Catheter care	34	1.62%
Cancer	33	1.58%
UTI	31	1.48%
Agitation	29	1.38%
Procedure	29	1.38%
SOB	24	1.15%

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What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire

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What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire.

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Abstract

Objectives: Out of hours (OOH) primary care services are a key element of community care at the end of life, yet there have been no previous attempts to describe the scope of this activity. We aimed to establish the proportion of Oxfordshire patients who were seen by the Out Of Hours service within the last 30 days of life, whether they were documented as in a palliative phase of care and the demographic and clinical features of these groups

Design Population based study linking a database of patient contacts with OOH primary care with the register of all deaths within Oxfordshire (600000 population) during 13 months.

Setting Oxfordshire

Participants Between 1/12/14 and 30/11/2015 there were 102,877 OOH contacts made by 67,943 patients with the OOH service.

Main outcome measures Proportion of patients dying in the Oxfordshire population who were seen by the Out Of Hours service within the last 30 days of life. Demographic and clinical features of these contacts.

Results 29.5% of all population deaths were seen by the OOH service in the last 30 days of life. Among the 1530 patients seen, patients whose palliative phase was documented (n=577, 36.4%) were slightly younger (median age = 83.5 vs 85.2 years, p<0.001) and were seen closer to death (median days to death = 2 v 8, p<0.001). More were assessed at home (59.8% vs 51.9%, p<0.001) and less were admitted to hospital (2.7% vs 18.0%, p<0.001).

Conclusions OOH services see around one third of all patients who die in a population. Most patients at the end of life are not documented as palliative by OOH services and are less likely to receive ongoing care at home.

Strengths and Limitations of this study

- This is the first study to use data linkage with death records to describe the true population at the end of life who contact the OOH service.
- The study highlights both the importance of the OOH primary care service in end of life care and the significant limitations of medical records studies which have used clinical coding of palliative care as a proxy for end of life contacts
- Our understanding of the proportion of these deaths which were palliative and the causes of death relied on the accuracy of clinical coding
- Our study focused on a single area of the UK due to restriction in access to OOH provider medical records

Introduction

The provision of primary care services outside core contracted hours is fundamental to the operation of the NHS.[1] In 2013-14, out of hours GP services (OOH) in England handled approximately 5.8 million cases, 3.3 million of which were face to face consultations, including 800,000 home visits.[2] For the majority of patients OOH primary care is provided by a clinician who does not know them, often with limited access to their medical record.[3]

In January 2015 the top research priority identified by the Palliative and end of life care Priority Setting Partnership was the provision of palliative care outside of working hours to help patients stay in their place of choice by managing crises.[4] Given that the majority of people with terminal illness do not wish to die in a hospital[5], OOH primary care services must be viewed as an integral part of end of life care provision.

Our current understanding of the true extent of end of life care provided by the OOH service is limited. OOH services do not routinely receive feedback on patient deaths following contact with the service. We previously analysed an OOH service database[6] and learned that patients whose needs were coded as palliative contacted the OOH service predominantly during weekend daytime periods, and that over a third had multiple contacts with the service. However, the study was limited because we were not able to identify all patients who had died and had contacted the service, thus underestimating the true proportion of patients with end of life care needs.

In order to understand how OOH care can best be provided at the end of life we need to understand the true extent of this workload and whether there are differences between patients who appear to be recognised as palliative by clinicians and those who are not. This study used data linkage to identify people who died in Oxfordshire over the course of a year who had contact with the OOH services in the 30 days before death and the clinical care that they received from the OOH service.

Methods

The Oxfordshire OOH service provides care to a population of over 600,000 people from 18:30pm – 08:00am on weekdays and 24 hour cover on weekends and bank holidays. Access to the service is via

the NHS 111 telephone advice line, where trained call handlers use the NHS Pathways algorithm to direct patients to the most appropriate service for their needs. Patients directed by 111 to the OOH service will receive an initial telephone consultation with an OOH clinician which may then lead to a base visit (patient comes to the OOH surgery to be seen), home visit or the case being passed to another care provider (such as 'hospital at home'). Patients can also be booked directly by 111 to an OOH base visit.

A database of all patient contacts with the Oxfordshire Out of Hours (OOH) service over 1 year from 01.12.14 to 30.11.2015 was created from the OOH Electronic Record System used by clinicians (Adastra).

Mortality data for Oxfordshire (population 600,000) over 13 months (1.12.14-31.12.15, to capture patients who died within 30 days of contact with the OOH service) was obtained via NHS Digital/Office of National Statistics, with Section 251 approval from the Confidentiality Advisory Group. This was linked by NHS number with Oxfordshire OOH service care records and was used to identify people who had contact with the OOH service in the 30 days prior to death. All patient identifiers were removed on entry to the database and data destruction was completed in accordance with NHS Digital requirements. Any contact without an NHS number was removed from the database, as repeat visits could not be assessed, as were those with a duplicate case ID. Contacts that were seen after death were also removed. Demographic data consisted of age, sex and Index of Multiple Deprivation score (available for 79% of contacts).[7] Service data included final contact type, outcome, date, clinical codes assigned and prescriptions issued. Mortality data included the date of death and all assigned ICD-10[8] causes of death. All assigned causes of death were included in the analysis in recognition of the fact that the most important or relevant cause of death may not be the first one listed on the certificate and therefore including only one cause would introduce significant bias.

Timings of calls were classified as evening 18:30-23:59, overnight 00:00-07:59 and daytime (i.e. weekends and bank holidays) 08:00-18:29. The number of days difference between contact and death was calculated using calendar days beginning at midnight. Weekend period was classified as 18:30 Friday until 08:00 Monday.

Those who died were also classified according to whether they had been documented by the service as palliative or not. We defined palliative patients as those who, at any contact with the OOH service in the study period, had been assigned a clinical code specific to palliative care, been referred to a hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication.

Appropriate subcutaneous medications were defined as medications as specified in the British National Formulary as being suitable for continuous subcutaneous infusion in palliative care. These included medications used for bowel colic and excessive respiratory secretions, confusion and restlessness, convulsions, nausea and vomiting and/or pain control.[9] This group was compared with all other patients who died within 30 days of contact. Further details regarding coding as supplied as supplementary information.

Validation

In order to validate the clinical codes applied by the OOH clinicians we estimated, based on previous coding validity studies[10] that analysis of 230 records would be required to establish the coding validity with a confidence level of 90% and 5% margin of error. A random selection of 230 records was obtained using SPSS, and the clinical code was compared by two authors (SG, HH) to the conclusion drawn by the clinician in the medical notes. The positive predictive value (PPV) of the clinical code for medical diagnosis or conclusion was 92.6%.

Statistical analysis

Demographic details and details concerning the cause of death were compared at a patient level, so that each patient was only considered once in the analysis. By contrast, the OOH contact and outcome were compared at an OOH contact level. Statistical analysis was performed using SPSS Version 22. T tests were used when comparing means, z tests when comparing proportions and Mann Witney U test when comparing medians. Logistic regression was performed to test associations for binary outcomes. This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

Results

Between 1/12/2014 -30/11/2015 there were 102,877 contacts, by 67,943 patients, with the Oxfordshire OOH service. In the 13 month period between 1/12/14 – 31/12/15, 5193 people died in Oxfordshire. Of the people who died, 1530 (29.5%) had contact with the OOH service in the 30 days prior to their death. These patients made 2661 contacts with the OOH service in the 30d prior to

their death, accounting for 2.57% of all contacts to the service over the 12 month study period. A further 791 contacts (with 752 patients) occurred *after* death, equating to 14.5% of all deaths and 0.76% of all contacts to the service. Contacts after death were excluded from further analyses.

Of those patients who had contact with the OOH service in the 30d prior to death, 381 (24.9%) made a contact in the last day of life (Figure 1). There was a median of 5 (Interquartile range (IQR) 1.75 – 13) days between final OOH contact and death and the median number of contacts with the OOH service in the 30 days prior to death was 1 (IQR 1 – 2). A similar proportion of deaths occurred on each day of the week (figure 2)

Tables 1 and 2 compare patients and patient contact features of those who died within 30 days of death with those who were alive at 30 days after initial OOH consultation. Patients who died were older, less deprived and more likely to be male. Patient contacts were more frequently in their own home and more likely to have their care escalated to an alternative provider (hospital, hospice, community care provider).

For those patients who died within 30 days the most commonly assigned clinical codes were palliative (27.3% of all codes assigned), advice (8.8%), medication requests (7.1%), lower respiratory tract infection (LRTI) (5.5%) or urinary tract infection (UTI) (4.2%) codes. By comparison, Ear, Nose and Throat disorder (ENT) (13.5%), UTI (6.0%), musculoskeletal disease (MSK) (5.3%), upper respiratory tract infection (URTI) (4.9%), and medication requests (4.2%) were the commonest codes in those alive at 30 days after index assessment (supplementary tables 1 and 2)

Acute events were the cause of death in 25% of patients. The commonest codes were types of cancer (45.6%) followed by cardiac disease (34.8%), LRTI (25.2%), dementia (23.9%), age related debility and other respiratory disease (both 15.2%) (see table 4 for full list).

Comparison between palliative patients and patients dying within 30 days not documented as palliative.

Patients who had contact with the OOH service in the 30 days prior to death were categorised into those who had been documented by the service as palliative (any palliative code assigned to record, hospice referral, or appropriate subcutaneous medication prescribed at any time), and those who had not.

557 patients (36.4%) were documented as palliative, and had 1310 contacts with the OOH service in the 30 days prior to death. By contrast, 973 patients (63.6%) were not documented as palliative, accounting for 1351 contacts.

Patients documented as palliative were younger than those not documented (median 83.5 years (IQR 74.1 – 89.6) vs 85.2years (IQR 78.3 – 91.1) ($p<0.001$, $z=4.45$), an association which was maintained after adjusting for sex and deprivation in multivariable logistic regression (Odds Ratio (OR) 0.98, $p<0.001$, 95% CI 0.97-0.99).

There were clear differences in the patterns of service use, depending on documentation of palliative phase of care. Patients documented as palliative were seen more frequently in the 30d prior to death (median 3 contacts, IQR 2-4, v median 2 contacts, IQR 1-3 $z = -12.813$ $p<0.001$) , and their final contact with the service was closer to the point of death (median number of days between final contact and death (IQR 1-6), days v 8 (IQR 3-17) days $z = -15.335$ ($p<0.001$), with 42.2% (v 15.1%) being seen on the day of death or day prior to death.

Patients documented as palliative presented less frequently at the weekend (67.2% v 70.4%; $z=-1.79$, $p=0.037$), and more frequently overnight (27%, vs 18.3%, $z=5.391$, $p<0.001$). They were more likely to be assessed at a home visit (59.8% v 51.9%; $z=4.094$, $p<0.001$) and less likely to be managed solely through telephone contact (43.2% vs 36.6%, $z=-3.508$, $p=0.002$).

The two groups of patients differed in the outcomes of contacts with the OOH service. Patients documented as palliative were less likely to be admitted to hospital following their assessment (2.7% vs 18.0% respectively, $z=-8.091$, $p<0.001$), but more likely to be referred for community input (12.7% vs 2.3%, $z=10.221$, $p<0.001$) or require no further follow up (40.8% vs 35.7%, $z=2.7$, $p=0.0035$) (Table 3).

In addition to palliative codes, the most common clinical codes assigned in those patients documented as palliative were medication related (7.4%), advice (6.35%), LRTI (2.8%), nausea and vomiting (2.0%) and catheter care (1.6%). In those patients not documented as palliative, a wider range of clinical codes were applied, the commonest were advice (10.8%), LRTI (8.4%), UTI (6.9%), medication related (6.2%) and shortness of breath (4.2%) (supplementary tables 3 and 4).

Causes of death in both groups are detailed in table 4. The highest proportion of deaths was due to malignancy in the group documented as palliative (70.7%); over twice that in those not documented as palliative (31.2%). There were similar proportions of patients with dementia as cause of death. Conversely, infections, myocardial infarction, pulmonary embolism, gastroenterological and endocrinological diseases were over twice as frequently assigned to patients in the group not

documented as palliative. Causes of death which would be considered acute events (acute kidney injury, myocardial infarction, pulmonary embolism, fracture, fall, trauma, stroke and sepsis) were applied to 18.1% of patients documented as palliative and 29.3% of those not documented as palliative.

Discussion

OOH GP services provide end of life care to almost a third of people who die in a population, frequently very close to death. This places OOH GP services at the forefront of end of life care provision. Patients at the end of life are more likely to contact the service overnight, likely in part due to the reduction in availability of other services at these times. Death administration contributes significantly to the workload of the OOH service, being required for 14.5% of all deaths. Just 0.4% of all contacts occurring within the 30 days prior to death result in a hospice admission.

Only 36.4% of patients contacting the service at the end of life were documented as palliative, hence studies relying on clinical coding of patient contacts as palliative will significantly under report the burden on the service. A large number of contacts in the 30 days prior to death result in a home visit irrespective of documentation of a palliative phase of care, reflecting significant frailty within this patient group. Patients not documented as palliative had a much higher rate of acute hospital admission, suggesting that initial management strategy is based on addressing an acute presenting illness syndrome with hospital based care in this group.

The only study which has used a similar methodology to explore OOH service use at the end of life reported a similarly high proportion (25%) of deceased patients contacting a Norwegian OOH service in the 4 weeks before death, with a much higher proportion (37%) referred to hospital at their OOH contact.[11]

Strengths and Limitations

This is the first study to accurately report the proportion of patients who die shortly after contact with OOH primary care by linking UK OOH records with mortality data. However, there are several limitations to our analysis. Our study is based in the English NHS, and we cannot comment on whether our results would extrapolate to other models of out of hours healthcare provision. By excluding deaths of patients living outside Oxfordshire we may have underestimated demands on the service. Our analysis was also limited to contacts within 30 days of death, however the majority

of contacts were within 7 days of death, suggesting that this has not significantly limited our conclusions.

In order to explore whether the service recognised the patient contact as palliative we relied on OOH clinicians assigning a palliative code to the patients record or a documenting an action only relevant to palliative care (prescribing subcutaneous medication or hospice referral). Since no other studies have attempted this form of classification we could not use a validated approach. It is likely that some patients who were recognised by the service as needing end of life care may have been misclassified in this analysis. However, the PPV of the clinical code for medical diagnosis or conclusion was higher than the average PPV found in a systematic review of studies using primary care medical records.[10] Similarly we relied on the accuracy of cause of death as recorded by either the regular general practitioner or hospital clinician. It is possible that acute events could be under reported in death certificates if active malignancy is present.

Implications

The OOH service is making a significant contribution to end of life care. Despite a majority of patients with terminal illness wishing to die at home, only a minority currently achieve this.[12] Enabling good deaths in the community is therefore a key component of OOH primary care provision. There is scope for debate on how best to provide a service to this patient group. One component of this must be improving planning and communication from the in hours GP to avoid OOH demands, and another might be the creation of dedicated palliative teams, operating in the OOH period. However, both of these measures will only support the third of patients at the end of life who are documented as palliative, and additional measures are needed to ensure that the OOH service is fit for managing all patients at the end of life, in terms of recognition of end of life, staff skill mix and resources.

Two thirds of patients who died within 30 days of OOH contact were not documented as being in a palliative phase of care. There will be patients for whom an acute life threatening syndrome has led to an OOH contact. The percentage of deaths which were due to acute events was 25% overall, in line with national estimates[13], and relatively higher in the group not documented as palliative (29.3%). In addition, clinicians may recognise patients to be at the end of life, but choose to use more immediately relevant clinical codes for the contact or be reluctant to use palliative codes for

patients who do not have cancer. Furthermore, there may be patients at the end of life where it is simply not recognised in the setting of multiple morbidity and frailty.

A greater number of acute, gastrointestinal, infection and cardiac codes were applied to patients who were not documented as palliative. Gastrointestinal conditions in particular have been highlighted previously as challenging to diagnose in prehospital urgent care settings.[14,15] Evolving OOH care services to include a greater range of POC blood and imaging diagnostics and tailored risk scores could offer clinicians support in triaging and managing these difficult presentations. Reviews of deaths are standard practice in acute trusts and are viewed as integral to learning and service improvement and in hours GPs are routinely informed of deaths of patients in their care. However, there is no routine mechanism to feedback to clinicians working in OOH services when deaths occur after contact. This deprives clinicians of the opportunity for valuable reflection and learning and services of the opportunity for improvement.[16] It is particularly relevant in light of the recent Care Quality Commission call[17] to end missed opportunities to learn from patient deaths. Following the Mazars report[18], there is an increased focus on more robust systems to learn from deaths of patients following contact with NHS trust services. This study may help OOH services prioritise deaths for mortality review to maximise learning.

Conclusion

The contribution of OOH primary care services to patients at the end of life has previously been under-researched and underestimated. This study demonstrates that almost a third of people who die have contact with an OOH service in the preceding 30 days. Further work to understand how OOH primary care can best meet the needs of patients at the end of life is required.

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Data sharing

No additional data available

Authors' contributions.

GH and DL conceived the study. RF developed the protocol, gained study permissions and developed the databases. RB DL and GH analysed the data. HH and SG validated the dataset. RB and GH drafted the manuscript and all authors contributed to interpretation of results and critical revision of the manuscript.

Competing interest statements

All authors have completed the *Unified Competing Interest form* (available on request from the corresponding author) and declare: no support from any organisation for the submitted work [or describe if any]; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Ethics committee approval

This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

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Figure Legends

Figure 1 Number of days between final OOH contact and death expressed as cumulative percentage

Figure 2 Number of deaths occurring on each day of the week

Tables

Table 1: Characteristics of patients contacting the service within 30 days of death compared to all other patients

	Patients within 30d of death (n = 1530)	**Patients not within 30d of death (n = 66413)**
Age (median, IQR)	84.9 (77.0 – 90.6) yrs	33.3 (12.2-- 59.2) yrs
Male (percentage, 95%CI)	44.3% (41.8 – 46.8)	41.6% (41.2 – 42.0)
IMD* score (mean, sd)	12.00 (9.30)	13.13 (9.67)

*Index of multiple deprivation

Table 2: Characteristics of patient contacts with the service within 30 days of death compared to all other contacts

	Contacts within 30d of death (n = 2661)	Contacts not within 30d of death (n = 100216)
Contact type (percentage (95%CI))		
Home visit	55.8% (53.9 – 57.7)	9.7% (9.5 – 9.9)
Base assessment	4.2% (3.4 – 5.0)	55.8% (55.5 – 56.1)
Telephone contact only	39.9% (38.0 – 41.8)	34.3% (34.0 – 34.6)
Time of contact (percentage (95%CI))		
Overnight 00:00-07:59	22.6% (21.0 – 24.2)	15.5% (15.3 – 15.7)
Evening 18:30-23:59	29.4% (27.7 – 31.1)	37.8% (37.5 – 38.1)
Daytime 08:00-18:29	48.0% (46.1 – 49.9)	46.7% (46.4 – 47.0)
Outcome of the contact (percentage (95%CI))		
Acute admission (hospital, A&E, ambulatory care unit)	10.5% (9.3 – 11.7)	7.43% (7.3 – 3.6)
Admission to hospice	0.4% (0.1 – 0.6)	0.03% (0.03 – 0.03)
Community input (Hospital at home, community nursing, social services, minor injury unit, mental health team)	7.4% (6.4 – 8.4)	1.2% (1.1 – 1.3)
Did not attend/unable to contact/left before treatment	0.3% (0.1 – 0.6)	1.4% (1.3 – 1.5)
GP Follow-up	38.2% (36.3 – 40.0)	36.8% (36.5 – 37.1)
No Follow-up	38.3% (36.3 – 40.0)	49.3% (49.0 – 49.6)
Other	5.1% (4.3 – 5.9)	3.8% (3.7 – 4.0)

Table 3: Outcomes of contacts with patients documented palliative v those not documented palliative

Outcome of contact	Documented as palliative		Not documented as palliative	
	Frequency	Percentage of contacts	Frequency	Percentage of contacts
Acute admission (hospital, A&E, EMU)	35	2.7%	243	18.0%
Admission to hospice	10	0.8%	0	0.0%
Community input (H@H, comm nursing, SS, MIU)	166	12.7%	31	2.3%
Unable to contact	2	0.2%	7	0.5%
GP FU	493	37.6%	522	38.6%
No FU	534	40.8%	482	35.7%
Other (OP clinic, passed to another provider)	68	5.2%	63	4.7%
Outcome missing	2	0.2%	3	0.2%
Total	1310	100.0%	1351	100.0%

Table 4: All assigned Causes of death by documented palliative / not and total

	Documented as palliative		Not documented as palliative		Total	
	frequency	percentage of patients	frequency	percentage of patients	frequency	percentage of patients
Malignancy	394	70.7	304	31.2	698	45.6
Cardiac disease excluding myocardial infarction	137	24.6	396	40.7	533	34.8
Acute lower respiratory infection	87	15.6	298	30.6	385	25.2
Dementia	121	21.7	244	25.1	365	23.9
Age-related physical debility	96	17.2	136	14.0	232	15.2
Respiratory disease	57	10.2	175	18.0	232	15.2
Stroke (haemorrhage or infarction)	56	10.1	124	12.7	180	11.8
Gastrointestinal disease	20	3.6	128	13.2	148	9.7
Type 2 diabetes mellitus without complications	39	7.0	105	10.8	144	9.4
Hypertension	37	6.6	104	10.7	141	9.2
Kidney disease	40	7.2	99	10.2	139	9.1
Peripheral vascular disease	21	3.8	51	5.2	72	4.7
Neurological disease	21	3.8	44	4.5	65	4.2
Urinary tract infection	6	1.1	53	5.4	59	3.9
Rheumatological disease	20	3.6	39	4.0	59	3.9
Other	13	2.3	40	4.1	53	3.5
Complication of procedure / surgery	14	2.5	32	3.3	46	3.0
Sepsis	8	1.4	37	3.8	45	2.9
Endocrinological disease	6	1.1	35	3.6	41	2.7
Parkinson's disease	12	2.2	28	2.9	40	2.6
Acute kidney failure	6	1.1	34	3.5	40	2.6
Acute myocardial infarction	8	1.4	31	3.2	39	2.5
Fracture	14	2.5	25	2.6	39	2.5
Pulmonary embolism	6	1.1	24	2.5	30	2.0
Infection (excluding LRTI & UTI)	4	0.7	25	2.6	29	1.9
Psychiatric	6	1.1	14	1.4	20	1.3
Non-malignant haematological	4	0.7	12	1.2	16	1.0
Traumatic	2	0.4	6	0.6	8	0.5
Fall	2	0.4	2	0.2	4	0.3
Drug related	0	0.0	4	0.4	4	0.3

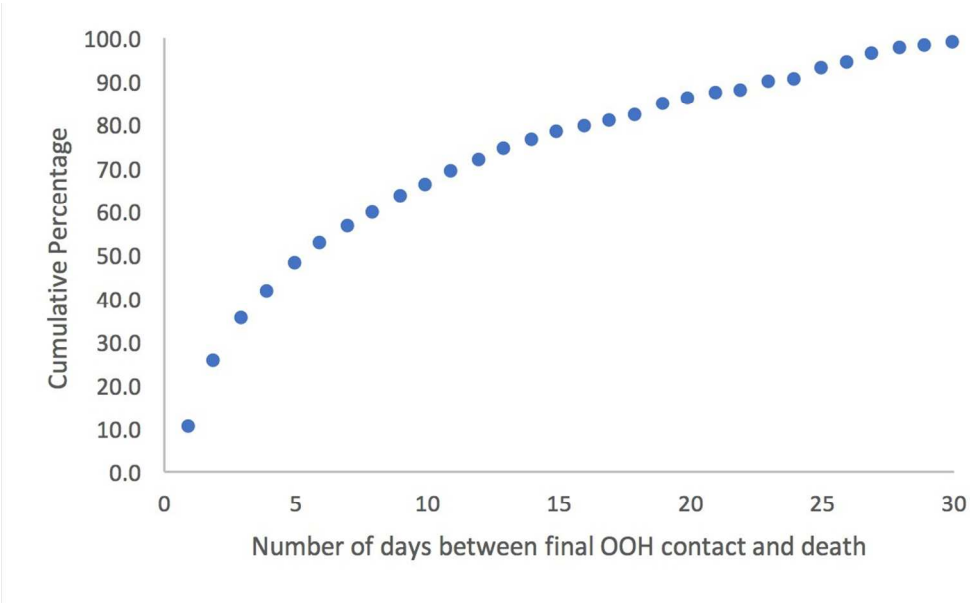

Figure 1: Number of days between final OOH contact and death expressed as cumulative percentage

106x63mm (300 x 300 DPI)

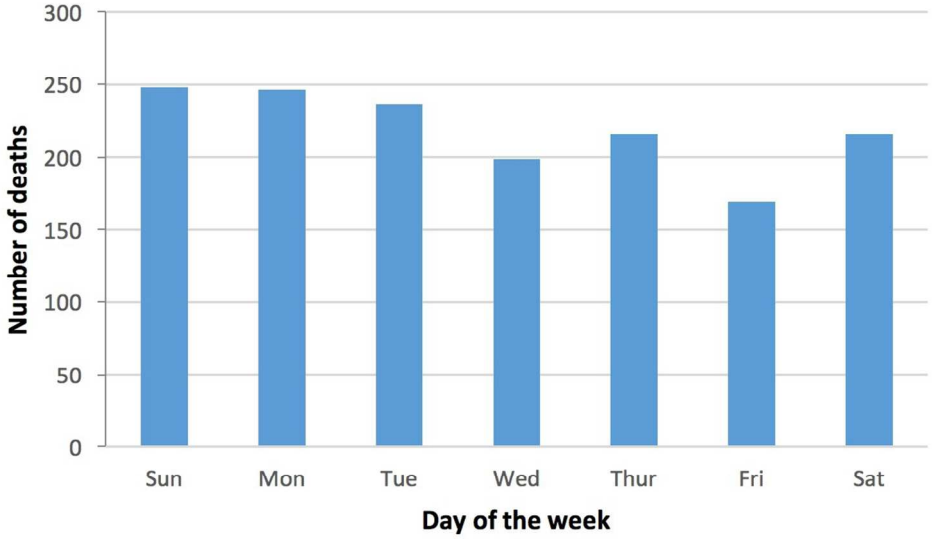

Figure 2: Number of deaths occurring on each day of the week

106x63mm (300 x 300 DPI)

Supplementary information

Coding of palliative patients

Palliative code

Patients were coded as palliative if they had any of the below palliative codes applied to their record at any time, during any contact, within the entire study period.

ZV57C [V]Palliative care

1Z0.. Terminal illness

8BA2. Terminal Care

Subcutaneous medication

Patients were also coded as palliative if they had been prescribed an appropriate subcutaneous medication at a contact within the 30 days prior to death.

This was determined via the hand searching of electronically recorded prescriptions, where the prescription specified subcutaneous administration or 'via a syringe driver' of any of the following medications as defined in the British National Formulary as being suitable for continuous subcutaneous infusion in palliative care.

Hyoscine hydrobromide	Hyoscine butylbromide
Glycopyrronium bromide	Haloperidol
Levomepromazine	Midazolam
Cyclizine	Metoclopramide
Octreotide	Morphine

Diamorphine hydrochloride.

Hospice referral

Patients were also coded as palliative if they had been admitted to a hospice as a result of a contact in the 30days prior to death.

This was therefore defined as any patients who had 'admission to hospice' as the documented contact outcome

Tables

Table 1: most commonly assigned clinical codes (>1%) to contacts in 30d prior to death

Clinical Code (grouped)	Frequency	% of all codes assigned.
Palliative	957	27.27%
Advice/reassurance	307	8.75%
Medication request/prescribed	248	7.07%
LRTI	194	5.53%
UTI	148	4.22%
SOB	95	2.71%
N&V	79	2.25%
Procedure	73	2.08%
Other Respiratory illness or symptom	73	2.08%
Catheter care	66	1.88%
Confusion/reduced GCS	55	1.57%
Pain	53	1.51%
Abdominal Pain	47	1.34%
Other	47	1.34%
Condition or symptom NOS	46	1.31%
Abnormal bloods	45	1.28%
Wound care	44	1.25%
Collapse or Fall	39	1.11%
Emergency treatment	36	1.03%
Agitation	35	1.00%
Cancer	35	1.00%

Table 2: Most commonly assigned clinical codes (>1%) to contacts alive at 30 days after OOH contact

Clinical code (grouped)	Frequency	% of all codes assigned
ENT symptom or condition	10507	13.49%
UTI	7305	6.00%
MSK disease	6443	5.30%
URTI	5909	4.86%
Medication request/prescribed	5141	4.23%
Advice/reassurance	4866	4.00%
Abdominal pain	4845	3.98%
Viral illness	4658	3.83%
Other respiratory symptoms or illness	4324	3.55%
Diagnosis not made	3733	3.07%
Skin infection	3470	2.85%
LRTI	3260	2.68%
Skin condition	3043	2.50%
Wound care	2708	2.23%
Gastroenteritis	2634	2.16%
Fever	2564	2.11%
Failed encounter/DNA	2405	1.98%
Mental health symptom/condition	2278	1.87%
N&V	2271	1.87%
Neurological condition	2158	1.77%
Accidental injury	2105	1.73%
GI disease or symptom	1995	1.64%
Catheter care	1950	1.60%
Eye problem	1876	1.54%
Oral disease	1752	1.44%
Urological disorder	1673	1.38%
Pregnancy, antenatal care or pregnancy complication	1376	1.13%
Diarrhoea	1314	1.08%
Chest pain/IHD	1281	1.05%

Table 3: Clinical codes most commonly assigned to contacts with patients not documented as palliative (codes accounting for >1% of all codes assigned.)

Clinical code (grouped)	Frequency	% of all codes
Advice	191	10.82%
LRTI	148	8.39%
UTI	121	6.86%
Medication request/prescribed	110	6.23%
SOB	74	4.19%
N&V	48	2.72%
Pain	39	2.21%
Catheter care	38	2.15%
Abdominal Pain	37	2.10%
Procedure	37	2.10%
Confusion	36	2.04%
Abnormal bloods	35	1.98%
Respiratory illness	32	1.81%
MSK disease	32	1.81%
Other	31	1.76%
Wound care	29	1.64%
Ill defined condition	27	1.53%
COPD	26	1.47%
Emergency treatment	25	1.42%
Fall	24	1.36%
Chest pain	22	1.25%
CVA	22	1.25%
Failed encounter	21	1.19%
Referral	20	1.13%
Dehydration	19	1.08%
Skin infection	19	1.08%
Unwell	18	1.02%
Sepsis	18	1.02%
GI bleed	18	1.02%

Table 4: Clinical codes (grouped) most commonly assigned to contacts with patients coded as palliative (i.e. codes accounting for >1% of all codes assigned.)

Documented as palliative		
Clinical code (grouped)	Frequency	% of all codes assigned
Palliative	1134	54.15%
Medication request/prescribed	155	7.40%
Advice	133	6.35%
LRTI	59	2.82%
N&V	42	2.01%
Catheter care	34	1.62%
Cancer	33	1.58%
UTI	31	1.48%
Agitation	29	1.38%
Procedure	29	1.38%
SOB	24	1.15%

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found		RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	Abstract, Page 1
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported			Introduction, page 3
Objectives	3	State specific objectives, including any prespecified hypotheses			Abstract, Page 1 Introduction, page 3
Methods					
Study Design	4	Present key elements of study design early in the paper			Methods, pages 3,4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			Methods, pages 3,4

Participants	6	*(a) Cohort study* - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study* - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study* - Give the eligibility criteria, and the sources and methods of selection of participants *(b) Cohort study* - For matched studies, give matching criteria and number of exposed and unexposed *Case-control study* - For matched studies, give matching criteria and the number of controls per case		RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	Methods, pages 3,4 Methods, page 5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	This is provided as supplementary material and is referred to in the methods section.
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group			

Bias	9	Describe any efforts to address potential sources of bias			
Study size	10	Explain how the study size was arrived at			
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study* - If applicable, explain how loss to follow-up was addressed *Case-control study* - If applicable, explain how matching of cases and controls was addressed *Cross-sectional study* - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population.	Methods, page 4 Methods page 4

				RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	
Linkage		..		RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	Methods, page 4
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (*e.g.*, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (*i.e.*, study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Methods, page 3,4
Descriptive data	14	(a) Give characteristics of study participants (*e.g.*, demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study* - summarise follow-up time (*e.g.*, average and total amount)			
Outcome data	15	*Cohort study* - Report numbers of outcome events or summary measures over time *Case-control study* - Report numbers in each exposure			

		category, or summary measures of exposure *Cross-sectional study* - Report numbers of outcome events or summary measures			
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses			
Discussion					
Key results	18	Summarise key results with reference to study objectives			
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	Discussion page 8,9
Interpretation	20	Give a cautious overall interpretation of results considering objectives,			

		limitations, multiplicity of analyses, results from similar studies, and other relevant evidence			
Generalisability	21	Discuss the generalisability (external validity) of the study results			
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based			
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	Page 10 – no additional data available.

*Reference: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

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What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire

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What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire.

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Abstract

Objectives: Out of hours (OOH) primary care services are a key element of community care at the end of life, yet there have been no previous attempts to describe the scope of this activity. We aimed to establish the proportion of Oxfordshire patients who were seen by the Out Of Hours service within the last 30 days of life, whether they were documented as in a palliative phase of care and the demographic and clinical features of these groups

Design Population based study linking a database of patient contacts with OOH primary care with the register of all deaths within Oxfordshire (600000 population) during 13 months.

Setting Oxfordshire

Participants Between 1/12/14 and 30/11/2015 there were 102,877 OOH contacts made by 67,943 patients with the OOH service.

Main outcome measures Proportion of patients dying in the Oxfordshire population who were seen by the Out Of Hours service within the last 30 days of life. Demographic and clinical features of these contacts.

Results 29.5% of all population deaths were seen by the OOH service in the last 30 days of life. Among the 1530 patients seen, patients whose palliative phase was documented (n=577, 36.4%) were slightly younger (median age = 83.5 vs 85.2 years, p<0.001) and were seen closer to death (median days to death = 2 v 8, p<0.001). More were assessed at home (59.8% vs 51.9%, p<0.001) and less were admitted to hospital (2.7% vs 18.0%, p<0.001).

Conclusions OOH services see around one third of all patients who die in a population. Most patients at the end of life are not documented as palliative by OOH services and are less likely to receive ongoing care at home.

Strengths and Limitations of this study

- This is the first study to use data linkage with death records to describe the true population at the end of life who contact the OOH service.
- The study highlights both the importance of the OOH primary care service in end of life care and the significant limitations of medical records studies which have used clinical coding of palliative care as a proxy for end of life contacts
- Our understanding of the proportion of these deaths which were palliative and the causes of death relied on the accuracy of clinical coding
- Our study focused on a single area of the UK due to restriction in access to OOH provider medical records

Introduction

The provision of primary care services outside core contracted hours is fundamental to the operation of the NHS.[1] In 2013-14, out of hours GP services (OOH) in England handled approximately 5.8 million cases, 3.3 million of which were face to face consultations, including 800,000 home visits.[2] For the majority of patients OOH primary care is provided by a clinician who does not know them, often with limited access to their medical record.[3]

In January 2015 the top research priority identified by the Palliative and end of life care Priority Setting Partnership was the provision of palliative care outside of working hours to help patients stay in their place of choice by managing crises.[4] Given that the majority of people in the UK with terminal illness do not wish to die in a hospital[5], OOH primary care services must be viewed as an integral part of end of life care provision.

Our current understanding of the true extent of end of life care provided by the OOH service is limited. OOH services do not routinely receive feedback on patient deaths following contact with the service. We previously analysed an OOH service database[6] and learned that patients whose needs were coded as palliative contacted the OOH service predominantly during weekend daytime periods, and that over a third had multiple contacts with the service. However, the study was limited because we were not able to identify all patients who had died and had contacted the service, thus underestimating the true proportion of patients with end of life care needs.

In order to understand how OOH care can best be provided at the end of life we need to understand the true extent of this workload and whether there are differences between patients who appear to be recognised as palliative by clinicians and those who are not. This study used data linkage to identify people who died in Oxfordshire over the course of a year who had contact with the OOH services in the 30 days before death and the clinical care that they received from the OOH service.

Methods

The Oxfordshire OOH service provides care to a population of over 600,000 people from 18:30pm – 08:00am on weekdays and 24 hour cover on weekends and bank holidays. Access to the service is via

the NHS 111 telephone advice line, where trained call handlers use the NHS Pathways algorithm to direct patients to the most appropriate service for their needs. Patients directed by 111 to the OOH service will receive an initial telephone consultation with an OOH clinician which may then lead to a base visit (patient comes to the OOH surgery to be seen), home visit or the case being passed to another care provider (such as 'hospital at home'). Patients can also be booked directly by 111 to an OOH base visit.

A database of all patient contacts with the Oxfordshire Out of Hours (OOH) service over 1 year from 01.12.14 to 30.11.2015 was created from the OOH Electronic Record System used by clinicians (Adastra).

Mortality data for Oxfordshire (population 600,000) over 13 months (1.12.14-31.12.15, to capture patients who died within 30 days of contact with the OOH service) was obtained via NHS Digital/Office of National Statistics, with Section 251 approval from the Confidentiality Advisory Group. This was linked by NHS number with Oxfordshire OOH service care records and was used to identify people who had contact with the OOH service in the 30 days prior to death. All patient identifiers were removed on entry to the database and data destruction was completed in accordance with NHS Digital requirements. Any contact without an NHS number was removed from the database, as repeat visits could not be assessed, as were those with a duplicate case ID. Contacts that were seen after death were also removed. Demographic data consisted of age, sex and Index of Multiple Deprivation score (available for 79% of contacts).[7] Service data included final contact type, outcome, date, clinical codes assigned and prescriptions issued. Mortality data included the date of death and all assigned ICD-10[8] causes of death. All assigned causes of death were included in the analysis in recognition of the fact that the most important or relevant cause of death may not be the first one listed on the certificate and therefore including only one cause would introduce significant bias.

Timings of calls were classified as evening 18:30-23:59, overnight 00:00-07:59 and daytime (i.e. weekends and bank holidays) 08:00-18:29. The number of days difference between contact and death was calculated using calendar days beginning at midnight. Weekend period was classified as 18:30 Friday until 08:00 Monday.

Those who died were also classified according to whether they had been documented by the service as palliative or not. We defined palliative patients as those who, at any contact with the OOH service in the study period, had been assigned a clinical code specific to palliative care, been referred to a hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication.

The clinical codes specific to palliative care were: ZV57C [V]Palliative care, 1Z0 Terminal illness, and 8BA2 Terminal Care.

Appropriate subcutaneous medications were defined as medications as specified in the British National Formulary as being suitable for continuous subcutaneous infusion in palliative care. These included medications used for bowel colic and excessive respiratory secretions, confusion and restlessness, convulsions, nausea and vomiting and/or pain control.[9] This group was compared with all other patients who died within 30 days of contact. Further details regarding coding are supplied as supplementary information.

Validation

In order to validate the clinical codes applied by the OOH clinicians we estimated, based on previous coding validity studies[10] that analysis of 230 records would be required to establish the coding validity with a confidence level of 90% and 5% margin of error. A random selection of 230 records was obtained using SPSS, and the clinical code was compared by two authors (SG, HH) to the conclusion drawn by the clinician in the medical notes. The positive predictive value (PPV) of the clinical code for medical diagnosis or conclusion was 92.6%.

Statistical analysis

Demographic details and details concerning the cause of death were compared at a patient level, so that each patient was only considered once in the analysis. By contrast, the OOH contact and outcome were compared at an OOH contact level. Statistical analysis was performed using SPSS Version 22. T tests were used when comparing means, z tests when comparing proportions and Mann Witney U test when comparing medians. Logistic regression was performed to test associations for binary outcomes. This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

Patient and Public Involvement

Patients were not involved in this study

Results

Between 1/12/2014 - 30/11/2015, 67,943 patients made 102,877 contacts, with the Oxfordshire OOH service. In the 13 month period between 1/12/14 – 31/12/15, 5193 people died in Oxfordshire. Of the people who died, 1530 (29.5%) had contact with the OOH service in the 30 days prior to their death. These patients made 2661 contacts with the OOH service in the 30d prior to their death, accounting for 2.57% of all contacts to the service over the 12 month study period. A further 791 contacts (with 752 patients) occurred *after* death, equating to 14.5% of all deaths and 0.76% of all contacts to the service. Contacts after death were excluded from further analyses.

Of those patients who had contact with the OOH service in the 30d prior to death, 381 (24.9%) made a contact in the last day of life (Figure 1). There was a median of 5 (Interquartile range (IQR) 1.75 – 13) days between final OOH contact and death and the median number of contacts with the OOH service in the 30 days prior to death was 1 (IQR 1 – 2). A similar proportion of deaths occurred on each day of the week (figure 2)

Tables 1 and 2 compare patients and patient contact features of those who died within 30 days of death with those who were alive at 30 days after initial OOH consultation. Patients who died were older, less deprived and more likely to be male. Patient contacts were more frequently in their own home and more likely to have their care escalated to an alternative provider (hospital, hospice, community care provider).

For those patients who died within 30 days the most commonly assigned clinical codes were palliative (27.3% of all codes assigned), advice (8.8%), medication requests (7.1%), lower respiratory tract infection (LRTI) (5.5%) or urinary tract infection (UTI) (4.2%) codes. By comparison, Ear, Nose and Throat disorder (ENT) (13.5%), UTI (6.0%), musculoskeletal disease (MSK) (5.3%), upper respiratory tract infection (URTI) (4.9%), and medication requests (4.2%) were the commonest codes in those alive at 30 days after index assessment (supplementary tables 1 and 2)

Acute events were the cause of death in 25% of patients. The commonest codes were types of cancer (45.6%) followed by cardiac disease (34.8%), LRTI (25.2%), dementia (23.9%), age related debility and other respiratory disease (both 15.2%) (see table 3 for full list).

Comparison between palliative patients and patients dying within 30 days not documented as palliative.

Patients who had contact with the OOH service in the 30 days prior to death were categorised into those who had been documented by the service as palliative (any palliative code assigned to record, hospice referral, or appropriate subcutaneous medication prescribed at any time), and those who had not.

557 patients (36.4%) were documented as palliative, and had 1310 contacts with the OOH service in the 30 days prior to death. By contrast, 973 patients (63.6%) were not documented as palliative, accounting for 1351 contacts.

Patients documented as palliative were younger than those not documented (median 83.5 years (IQR 74.1 – 89.6) vs 85.2 years (IQR 78.3 – 91.1) ($p<0.001$, $z=4.45$), an association which was maintained after adjusting for sex and deprivation in multivariable logistic regression (Odds Ratio (OR) 0.98, $p<0.001$, 95% CI 0.97-0.99).

There were clear differences in the patterns of service use, depending on documentation of palliative phase of care. Patients documented as palliative were seen more frequently in the 30d prior to death (median 3 contacts, IQR 2-4, v median 2 contacts, IQR 1-3 $z = -12.813$ $p<0.001$) , and their final contact with the service was closer to the point of death (median number of days between final contact and death (IQR 1-6), days v 8 (IQR 3-17) days $z = -15.335$ ($p<0.001$), with 42.2% (v 15.1%) being seen on the day of death or day prior to death.

Patients documented as palliative presented less frequently at the weekend (67.2% v 70.4%; $z=-1.79$, $p=0.037$), and more frequently overnight (27%, vs 18.3%, $z=5.391$, $p<0.001$). They were more likely to be assessed at a home visit (59.8% v 51.9%; $z=4.094$, $p<0.001$) and less likely to be managed solely through telephone contact (43.2% vs 36.6%, $z=-3.508$, $p=0.002$).

The two groups of patients differed in the outcomes of contacts with the OOH service. Patients documented as palliative were less likely to be admitted to hospital following their assessment (2.7% vs 18.0% respectively, $z=-8.091$, $p<0.001$), but more likely to be referred for community input (12.7% vs 2.3%, $z=10.221$, $p<0.001$) or require no further follow up (40.8% vs 35.7%, $z=2.7$, $p=0.0035$) (Table 4).

In addition to palliative codes, the most common clinical codes assigned in those patients documented as palliative were medication related (7.4%), advice (6.35%), LRTI (2.8%), nausea and vomiting (2.0%) and catheter care (1.6%). In those patients not documented as palliative, a wider range of clinical codes were applied, the commonest were advice (10.8%), LRTI (8.4%), UTI (6.9%), medication related (6.2%) and shortness of breath (4.2%) (supplementary tables 3 and 4).

Causes of death in both groups are detailed in table 3. The highest proportion of deaths was due to malignancy in the group documented as palliative (70.7%); over twice that in those not documented as palliative (31.2%). There were similar proportions of patients with dementia as cause of death. Conversely, infections, myocardial infarction, pulmonary embolism, gastroenterological and endocrinological diseases were over twice as frequently assigned to patients in the group not documented as palliative. Causes of death which would be considered acute events (acute kidney injury, myocardial infarction, pulmonary embolism, fracture, fall, trauma, stroke and sepsis) were applied to 18.1% of patients documented as palliative and 29.3% of those not documented as palliative.

Discussion

OOH GP services provide end of life care to almost a third of people who die in a population, frequently very close to death. This places OOH GP services at the forefront of end of life care provision. Patients at the end of life are more likely to contact the service overnight, likely in part due to the reduction in availability of other services at these times. Death administration contributes significantly to the workload of the OOH service, being required for 14.5% of all deaths. Just 0.4% of all contacts occurring within the 30 days prior to death result in a hospice admission.

Only 36.4% of patients contacting the service at the end of life were documented as palliative, hence studies relying on clinical coding of patient contacts as palliative will significantly under report the burden on the service. A large number of contacts in the 30 days prior to death result in a home visit irrespective of documentation of a palliative phase of care, reflecting significant frailty within this patient group. Patients not documented as palliative had a much higher rate of acute hospital admission, suggesting that initial management strategy is based on addressing an acute presenting illness syndrome with hospital based care in this group.

The only study which has used a similar methodology to explore OOH service use at the end of life reported a similarly high proportion (25%) of deceased patients contacting a Norwegian OOH service in the 4 weeks before death, with a much higher proportion (37%) referred to hospital at their OOH contact.[11]

Strengths and Limitations

This is the first study to accurately report the proportion of patients who die shortly after contact with OOH primary care by linking UK OOH records with mortality data. However, there are several

limitations to our analysis. Our study is based in the English NHS, and we cannot comment on whether our results would extrapolate to other models of out of hours healthcare provision. By excluding deaths of patients living outside Oxfordshire we may have underestimated demands on the service. Our analysis was also limited to contacts within 30 days of death, however the majority of contacts were within 7 days of death, suggesting that this has not significantly limited our conclusions.

In order to explore whether the service recognised the patient contact as palliative we relied on OOH clinicians assigning a palliative code to the patients record or a documenting an action only relevant to palliative care (prescribing subcutaneous medication or hospice referral). Since no other studies have attempted this form of classification we could not use a validated approach. It is likely that some patients who were recognised by the service as needing end of life care may have been misclassified in this analysis. However, the PPV of the clinical code for medical diagnosis or conclusion was higher than the average PPV found in a systematic review of studies using primary care medical records.[10] Similarly we relied on the accuracy of cause of death as recorded by either the regular general practitioner or hospital clinician. It is possible that acute events could be under reported in death certificates if active malignancy is present.

Implications

The OOH service is making a significant contribution to end of life care. Despite a majority of patients with terminal illness wishing to die at home, only a minority currently achieve this.[12] Enabling good deaths in the community is therefore a key component of OOH primary care provision. There is scope for debate on how best to provide a service to this patient group. One component of this must be improving planning and communication from the in hours GP to avoid OOH demands, and another might be the creation of dedicated palliative teams, operating in the OOH period. However, both of these measures will only support the third of patients at the end of life who are documented as palliative, and additional measures are needed to ensure that the OOH service is fit for managing all patients at the end of life, in terms of recognition of end of life, staff skill mix and resources.

Two thirds of patients who died within 30 days of OOH contact were not documented as being in a palliative phase of care. There will be patients for whom an acute life threatening syndrome has led to an OOH contact. The percentage of deaths which were due to acute events was 25% overall, in

line with national estimates[13], and relatively higher in the group not documented as palliative (29.3%). In addition, clinicians may recognise patients to be at the end of life, but choose to use more immediately relevant clinical codes for the contact or be reluctant to use palliative codes for patients who do not have cancer. Furthermore, there may be patients at the end of life where it is simply not recognised in the setting of multiple morbidity and frailty.

A greater number of acute, gastrointestinal, infection and cardiac codes were applied to patients who were not documented as palliative. Gastrointestinal conditions in particular have been highlighted previously as challenging to diagnose in prehospital urgent care settings.[14,15] Evolving OOH care services to include a greater range of POC blood and imaging diagnostics and tailored risk scores could offer clinicians support in triaging and managing these difficult presentations. Reviews of deaths are standard practice in acute trusts and are viewed as integral to learning and service improvement and in hours GPs are routinely informed of deaths of patients in their care. However, there is no routine mechanism to feedback to clinicians working in OOH services when deaths occur after contact. This deprives clinicians of the opportunity for valuable reflection and learning and services of the opportunity for improvement.[16] It is particularly relevant in light of the recent Care Quality Commission call[17] to end missed opportunities to learn from patient deaths. Following the Mazars report[18], there is an increased focus on more robust systems to learn from deaths of patients following contact with NHS trust services. This study may help OOH services prioritise deaths for mortality review to maximise learning.

Conclusion

The contribution of OOH primary care services to patients at the end of life has previously been under-researched and underestimated. This study demonstrates that almost a third of people who die have contact with an OOH service in the preceding 30 days. Further work to understand how OOH primary care can best meet the needs of patients at the end of life is required.

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Data sharing

No additional data available

Authors' contributions.

GH and DL conceived the study. RF developed the protocol, gained study permissions and developed the databases. RB DL and GH analysed the data. HH and SG validated the dataset. RB and GH drafted the manuscript and all authors contributed to interpretation of results and critical revision of the manuscript.

Competing interest statements

All authors have completed the *Unified Competing Interest form* (available on request from the corresponding author) and declare: no support from any organisation for the submitted work [or describe if any]; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Ethics committee approval

This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

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Figure Legends

Figure 1 Number of days between final OOH contact and death expressed as cumulative percentage

Figure 2 Number of deaths occurring on each day of the week

Tables

Table 1: Characteristics of patients contacting the service within 30 days of death compared to all other patients

	Patients within 30d of death (n = 1530)	**Patients not within 30d of death (n = 66413)**
Age (median, IQR)	84.9 (77.0 – 90.6) yrs	33.3 (12.2-- 59.2) yrs
Male (percentage, 95%CI)	44.3% (41.8 – 46.8)	41.6% (41.2 – 42.0)
IMD* score (mean, sd)	12.00 (9.30)	13.13 (9.67)

*Index of multiple deprivation

Table 2: Characteristics of patient contacts with the service within 30 days of death compared to all other contacts

	Contacts within 30d of death (n = 2661)	Contacts not within 30d of death (n = 100216)
Contact type (percentage (95%CI))		
Home visit	55.8% (53.9 – 57.7)	9.7% (9.5 – 9.9)
Base assessment	4.2% (3.4 – 5.0)	55.8% (55.5 – 56.1)
Telephone contact only	39.9% (38.0 – 41.8)	34.3% (34.0 – 34.6)
Time of contact (percentage (95%CI))		
Overnight 00:00-07:59	22.6% (21.0 – 24.2)	15.5% (15.3 – 15.7)
Evening 18:30-23:59	29.4% (27.7 – 31.1)	37.8% (37.5 – 38.1)
Daytime 08:00-18:29	48.0% (46.1 – 49.9)	46.7% (46.4 – 47.0)
Outcome of the contact (percentage (95%CI))		
Acute admission (hospital, emergency department (ED), ambulatory care unit)	10.5% (9.3 – 11.7)	7.43% (7.3 – 3.6)
Admission to hospice	0.4% (0.1 – 0.6)	0.03% (0.03 – 0.03)
Community input (Hospital at home, community nursing, social services, minor injury unit, mental health team)	7.4% (6.4 – 8.4)	1.2% (1.1 – 1.3)
Did not attend/unable to contact/left before treatment	0.3% (0.1 – 0.6)	1.4% (1.3 – 1.5)
GP Follow-up	38.2% (36.3 – 40.0)	36.8% (36.5 – 37.1)
No Follow-up	38.3% (36.3 – 40.0)	49.3% (49.0 – 49.6)
Other	5.1% (4.3 – 5.9)	3.8% (3.7 – 4.0)

Table 3: All assigned Causes of death by documented palliative / not and total

	Documented as palliative		Not documented as palliative		Total	
	frequency	percentage of patients	frequency	percentage of patients	frequency	percentage of patients
Malignancy	394	70.7	304	31.2	698	45.6
Cardiac disease excluding myocardial infarction	137	24.6	396	40.7	533	34.8
Acute lower respiratory infection	87	15.6	298	30.6	385	25.2
Dementia	121	21.7	244	25.1	365	23.9
Age-related physical debility	96	17.2	136	14.0	232	15.2
Respiratory disease	57	10.2	175	18.0	232	15.2
Stroke (haemorrhage or infarction)	56	10.1	124	12.7	180	11.8
Gastrointestinal disease	20	3.6	128	13.2	148	9.7
Type 2 diabetes mellitus without complications	39	7.0	105	10.8	144	9.4
Hypertension	37	6.6	104	10.7	141	9.2
Kidney disease	40	7.2	99	10.2	139	9.1
Peripheral vascular disease	21	3.8	51	5.2	72	4.7
Neurological disease	21	3.8	44	4.5	65	4.2
Urinary tract infection	6	1.1	53	5.4	59	3.9
Rheumatological disease	20	3.6	39	4.0	59	3.9
Other	13	2.3	40	4.1	53	3.5
Complication of procedure / surgery	14	2.5	32	3.3	46	3.0
Sepsis	8	1.4	37	3.8	45	2.9
Endocrinological disease	6	1.1	35	3.6	41	2.7
Parkinson's disease	12	2.2	28	2.9	40	2.6
Acute kidney failure	6	1.1	34	3.5	40	2.6
Acute myocardial infarction	8	1.4	31	3.2	39	2.5
Fracture	14	2.5	25	2.6	39	2.5
Pulmonary embolism	6	1.1	24	2.5	30	2.0
Infection (excluding LRTI & UTI)	4	0.7	25	2.6	29	1.9
Psychiatric	6	1.1	14	1.4	20	1.3
Non-malignant haematological	4	0.7	12	1.2	16	1.0
Traumatic	2	0.4	6	0.6	8	0.5
Fall	2	0.4	2	0.2	4	0.3
Drug related	0	0.0	4	0.4	4	0.3

Table 4: Outcomes of contacts with patients documented palliative v those not documented palliative

Outcome of contact	Documented as palliative		Not documented as palliative	
	Frequency	Percentage of contacts	Frequency	Percentage of contacts
Acute admission (hospital, A&E, EMU)	35	2.7%	243	18.0%
Admission to hospice	10	0.8%	0	0.0%
Community input (H@H, comm nursing, SS, MIU)	166	12.7%	31	2.3%
Unable to contact	2	0.2%	7	0.5%
GP FU	493	37.6%	522	38.6%
No FU	534	40.8%	482	35.7%
Other (OP clinic, passed to another provider)	68	5.2%	63	4.7%
Outcome missing	2	0.2%	3	0.2%
Total	1310	100.0%	1351	100.0%

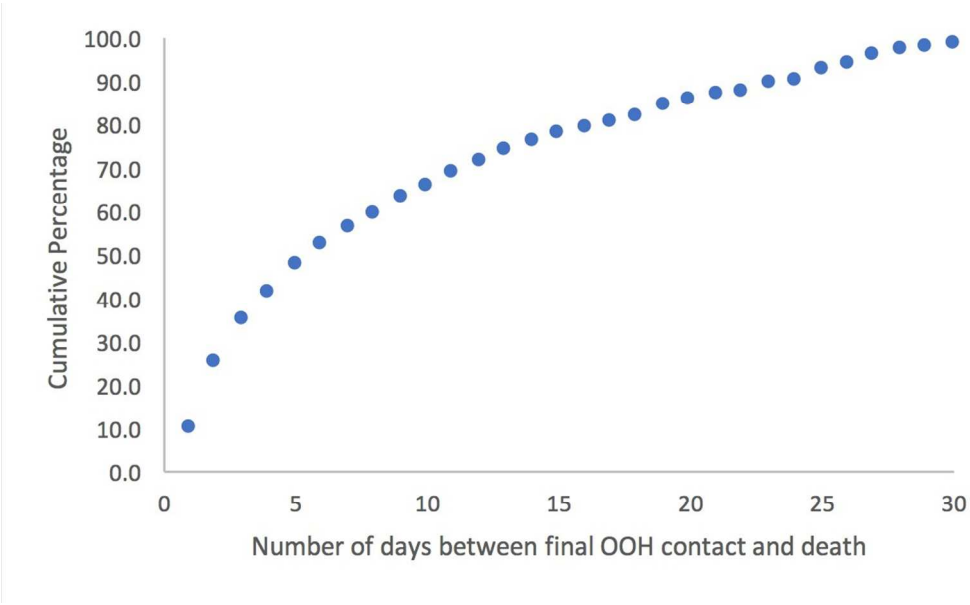

Figure 1: Number of days between final OOH contact and death expressed as cumulative percentage

106x63mm (300 x 300 DPI)

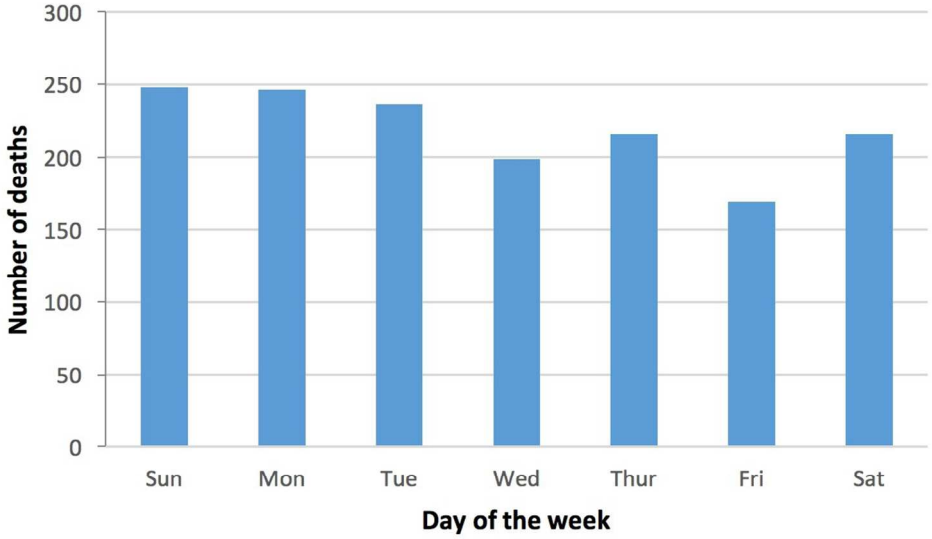

Figure 2: Number of deaths occurring on each day of the week

106x63mm (300 x 300 DPI)

Supplementary information

Coding of palliative patients

Palliative code

Patients were coded as palliative if they had any of the below palliative codes applied to their record at any time, during any contact, within the entire study period.

ZV57C [V]Palliative care

1Z0.. Terminal illness

8BA2. Terminal Care

Subcutaneous medication

Patients were also coded as palliative if they had been prescribed an appropriate subcutaneous medication at a contact within the 30 days prior to death.

This was determined via the hand searching of electronically recorded prescriptions, where the prescription specified subcutaneous administration or 'via a syringe driver' of any of the following medications as defined in the British National Formulary as being suitable for continuous subcutaneous infusion in palliative care.

Hyoscine hydrobromide	Hyoscine butylbromide
Glycopyrronium bromide	Haloperidol
Levomepromazine	Midazolam
Cyclizine	Metoclopramide
Octreotide	Morphine

Diamorphine hydrochloride.

Hospice referral

Patients were also coded as palliative if they had been admitted to a hospice as a result of a contact in the 30days prior to death.

This was therefore defined as any patients who had 'admission to hospice' as the documented contact outcome

Tables

Table 1: most commonly assigned clinical codes (>1%) to contacts in 30d prior to death

Clinical Code (grouped)	Frequency	% of all codes assigned.
Palliative	957	27.27%
Advice/reassurance	307	8.75%
Medication request/prescribed	248	7.07%
LRTI	194	5.53%
UTI	148	4.22%
SOB	95	2.71%
N&V	79	2.25%
Procedure	73	2.08%
Other Respiratory illness or symptom	73	2.08%
Catheter care	66	1.88%
Confusion/reduced GCS	55	1.57%
Pain	53	1.51%
Abdominal Pain	47	1.34%
Other	47	1.34%
Condition or symptom NOS	46	1.31%
Abnormal bloods	45	1.28%
Wound care	44	1.25%
Collapse or Fall	39	1.11%
Emergency treatment	36	1.03%
Agitation	35	1.00%
Cancer	35	1.00%

Table 2: Most commonly assigned clinical codes (>1%) to contacts alive at 30 days after OOH contact

Clinical code (grouped)	Frequency	% of all codes assigned
ENT symptom or condition	10507	13.49%
UTI	7305	6.00%
MSK disease	6443	5.30%
URTI	5909	4.86%
Medication request/prescribed	5141	4.23%
Advice/reassurance	4866	4.00%
Abdominal pain	4845	3.98%
Viral illness	4658	3.83%
Other respiratory symptoms or illness	4324	3.55%
Diagnosis not made	3733	3.07%
Skin infection	3470	2.85%
LRTI	3260	2.68%
Skin condition	3043	2.50%
Wound care	2708	2.23%
Gastroenteritis	2634	2.16%
Fever	2564	2.11%
Failed encounter/DNA	2405	1.98%
Mental health symptom/condition	2278	1.87%
N&V	2271	1.87%
Neurological condition	2158	1.77%
Accidental injury	2105	1.73%
GI disease or symptom	1995	1.64%
Catheter care	1950	1.60%
Eye problem	1876	1.54%
Oral disease	1752	1.44%
Urological disorder	1673	1.38%
Pregnancy, antenatal care or pregnancy complication	1376	1.13%
Diarrhoea	1314	1.08%
Chest pain/IHD	1281	1.05%

Table 3: Clinical codes most commonly assigned to contacts with patients not documented as palliative (codes accounting for >1% of all codes assigned.)

Clinical code (grouped)	Frequency	% of all codes
Advice	191	10.82%
LRTI	148	8.39%
UTI	121	6.86%
Medication request/prescribed	110	6.23%
SOB	74	4.19%
N&V	48	2.72%
Pain	39	2.21%
Catheter care	38	2.15%
Abdominal Pain	37	2.10%
Procedure	37	2.10%
Confusion	36	2.04%
Abnormal bloods	35	1.98%
Respiratory illness	32	1.81%
MSK disease	32	1.81%
Other	31	1.76%
Wound care	29	1.64%
Ill defined condition	27	1.53%
COPD	26	1.47%
Emergency treatment	25	1.42%
Fall	24	1.36%
Chest pain	22	1.25%
CVA	22	1.25%
Failed encounter	21	1.19%
Referral	20	1.13%
Dehydration	19	1.08%
Skin infection	19	1.08%
Unwell	18	1.02%
Sepsis	18	1.02%
GI bleed	18	1.02%

Table 4: Clinical codes (grouped) most commonly assigned to contacts with patients coded as palliative (i.e. codes accounting for >1% of all codes assigned.)

Documented as palliative		
Clinical code (grouped)	Frequency	% of all codes assigned
Palliative	1134	54.15%
Medication request/prescribed	155	7.40%
Advice	133	6.35%
LRTI	59	2.82%
N&V	42	2.01%
Catheter care	34	1.62%
Cancer	33	1.58%
UTI	31	1.48%
Agitation	29	1.38%
Procedure	29	1.38%
SOB	24	1.15%

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found		RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	Abstract, Page 1
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported			Introduction, page 3
Objectives	3	State specific objectives, including any prespecified hypotheses			Abstract, Page 1 Introduction, page 3
Methods					
Study Design	4	Present key elements of study design early in the paper			Methods, pages 3,4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			Methods, pages 3,4

Participants	6	*(a) Cohort study* - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study* - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study* - Give the eligibility criteria, and the sources and methods of selection of participants *(b) Cohort study* - For matched studies, give matching criteria and number of exposed and unexposed *Case-control study* - For matched studies, give matching criteria and the number of controls per case		RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	Methods, pages 3,4 Methods, page 5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	This is provided as supplementary material and is referred to in the methods section.
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group			

Bias	9	Describe any efforts to address potential sources of bias			
Study size	10	Explain how the study size was arrived at			
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study* - If applicable, explain how loss to follow-up was addressed *Case-control study* - If applicable, explain how matching of cases and controls was addressed *Cross-sectional study* - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population.	Methods, page 4 Methods page 4

				RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	
Linkage		..		RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	Methods, page 4
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (*e.g.*, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (*i.e.*, study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Methods, page 3,4
Descriptive data	14	(a) Give characteristics of study participants (*e.g.*, demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study* - summarise follow-up time (*e.g.*, average and total amount)			
Outcome data	15	*Cohort study* - Report numbers of outcome events or summary measures over time *Case-control study* - Report numbers in each exposure			

		category, or summary measures of exposure *Cross-sectional study* - Report numbers of outcome events or summary measures			
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses			
Discussion					
Key results	18	Summarise key results with reference to study objectives			
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	Discussion page 8,9
Interpretation	20	Give a cautious overall interpretation of results considering objectives,			

		limitations, multiplicity of analyses, results from similar studies, and other relevant evidence			
Generalisability	21	Discuss the generalisability (external validity) of the study results			
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based			
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	Page 10 – no additional data available.

*Reference: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.