

Health Service Research

General practitioners' provision of end-of-life care and associations with dying at home: a registry-based longitudinal study

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Abstract

Background: General practitioners (GPs) may play an important role in providing end-of-life care to community-dwelling people.

Objective: To investigate patients' contacts with GPs, GPs' interdisciplinary collaboration, out-of-hours services and hospitalizations in the last 13 weeks of life and associations with dying at home. Second, investigate whether GP contacts were associated with fewer out-of-hours contacts or days hospitalized.

Methods: Individually linked data from the Norwegian Cause of Death Registry, Norwegian Patient Registry, Statistics Norway and Control and Payment of Reimbursement to Health Service Providers database for all 80 813 deceased people in Norway within 2012–13. Outcomes were analyzed with logistic regression and negative binomial multilevel mixed-effect models.

Results: Overall, 1% of people received GP home visits in Week 13 and 4.6% in the last week before death. During the last 4 weeks of life, 9.2% received one or more GP home visits. Altogether, 6.6% received one or more home visits when the GP had one or more interdisciplinary collaborations during the last 4 weeks, of which <3% died at home. GP office consultations decreased towards the end of life. The likelihood of home death versus another location increased in relation to GP home visits [one home visit odds ratio (OR) 1.92, confidence interval (CI) 1.71–2.15; two or more OR 3.49, CI 3.08–3.96] and GP interdisciplinary collaboration (one contact OR 1.76, CI 1.59–1.96; two or more OR 2.52, CI 2.32–2.74).

Conclusions: GPs play a role in enabling people to die at home by performing home visits and collaborating with other health care personnel. Only a minority received such services in Norway.

Key words: Death/epidemiology, general practice, home visit, palliative care, registries, terminal care.

Background

General practitioners (GPs) may play an important role in providing primary end-of-life care to community-dwelling people (1–4). The

majority of people wish to spend their remaining life at home; however, specialized palliative care is unavailable for many dying people (4–6). Identified quality indicators for appropriate and inappropriate

Key messages

- General practitioner (GP) home visits and interdisciplinary collaboration were associated with home death.
- Few received services indicating appropriate end-of-life care from GPs.
- The potential for GPs to deliver this care is currently not utilized.

end-of-life care include contacts with the patient's GP, emergency department admissions, hospital admissions, late initiation of palliative care and dying at home versus the hospital (7). Factors such as palliative care training, recognition of palliative care needs and available resources may influence GPs' provision of end-of-life care (8,9). GP home visits and interdisciplinary collaboration increase the likelihood of home death for cancer patients (1,2,10,11).

In Norway, most citizens are registered with a GP through the national health care system (12). Most GPs have long-term patients ensuring continuity of care (13). They provide care for patients during daytime and out of hours (OOH) for medical emergencies in most municipalities; larger cities may have separate 24-hour emergency services. GPs are gatekeepers to specialized health care services. Together with home nursing services, they are the foundation of primary health care.

Previous studies have provided valuable knowledge about GPs' follow-up of patients at the end of life but have mainly used self-report from GPs and/or focused on cancer patients (2,10,11,14–20). These findings are not generalizable to all dying people. We found only one previous study reporting GPs' provision of palliative end-of-life care in a general population while considering hospital and emergency department admissions; however, the majority of included persons had cancer (1). They did not specify GP contact type or consider interdisciplinary collaboration.

We aimed to investigate patients' contacts with GPs (office consultations and home visits), GPs interdisciplinary collaboration, primary care OOH services, and hospitalizations in the last 13 weeks of life for people with all causes of death and how these contacts were associated with dying at home in Norway. Second, we investigated whether GP contacts were associated with fewer OOH contacts or days hospitalized during the last 13 weeks of life.

Methods

We used individually linked data from the Norwegian Cause of Death Registry (NCoDR), the Norwegian Patient Registry (NPR), Statistics Norway and the Control and Payment of Reimbursement to Health Service Providers Database (KUHR) for all decedents in Norway within 2012–13 ($n = 80\,813$), excluding those with missing information on patient identifier ($n = 135$), place of death ($n = 2484$), or where country of residence was not Norway ($n = 15$). Death date was set as Day 0 and all events decremented for each day for the last 13 weeks (3 months).

Outcomes

Place of death provided by NCoDR was grouped into home, nursing home (NH), hospital and other (abroad, under transportation to hospital and other). KUHR provided electronic billing claims from GPs and primary care OOH services (hereafter, OOH services). For every contact, a claim is made, identifying the physician and the patient and gives information about diagnosis and fee codes. OOH daytime contacts in Bergen municipality are not included because they are not registered in KUHR. Billing claims with errors ($n = 42$)

were excluded. This left 307 366 billing claims that were home visits, office consultations or contacts with other health care personnel regarding the patient (253 663 GPs and 53 703 OOH). We used GP contacts with other health care personnel as an indicator of interdisciplinary collaboration (hereafter, interdisciplinary collaboration). We defined 'appropriate follow-up' from GPs at the end of life as receiving one or more home visits and one or more interdisciplinary collaborations.

NPR provided information on hospital admissions. We excluded 45 admissions coded as starting after death. For 3923 hospitalizations, discharge dates after death were set to the day of death.

Covariates

NCoDR provided information about cause of death and age. Cause of death was coded according to the International Statistical Classification of Diseases, Tenth Revision and grouped into: Cancer (C00-D49), Circulatory (I00-I99), Respiratory (J00-J99), Dementia (F00-F03, G30), External (V00-Y99) and Other (specified) (21). Age was given in 5-year intervals. Statistics Norway provided information on education, marital status, children and municipality centrality. Education indicated highest completed education level, categorized as primary school, high school or college/university. People with unknown education level were categorized as primary school ($n = 1422$, 2.4%). Marital status was defined as 'not married' if a person was unmarried/widowed/divorced/separated/separated partner/divorced partner/surviving partner and defined as 'married' if a person was married/registered partner. Numbers of living children of the deceased at the time of death were categorized as 0, 1 or ≥ 2 . Municipality centrality relates to geographical distance to a centre with important functions, categorized from 0 (least central) to 3 (most central) (22).

Statistical analyses

Characteristics of the population were described as number of people and percentages for categorical variables and median and 25th–75th percentile for continuous variables.

People in long-term NH care receive follow-up from NH physicians instead of their GP. Thus, they are not exposed to GP care but remain on their personal GPs' patient list. To account for this, we generated the probability of being in long-term care with data from the National Registry for statistics on municipal health care services (IPLOS) and NCoDR (23). We used factors available in both data sets (age, sex, place of death, cause of death main categories by European Shortlist for Causes of Death (24), death certificate, death abroad, special circumstances, autopsy and police report). The model had excellent fit and prediction [receiver operating characteristic area 0.901 (confidence interval (CI) 0.898–0.903)]. We used this predicted probability as a propensity score covariate in the models using the NCoDR/NPR/Statistics Norway/KUHR data set.

Logistic regression modeling estimated associations between dying at home relative to any other location (NH, hospital and other) and factors of interest: number of GP home visits (0, 1, ≥ 2), GP office consultations (0, 1, ≥ 2), GP interdisciplinary collaboration

(0, 1, ≥ 2), OOH home visits (0, 1, ≥ 2), OOH consultations (0, 1, ≥ 2) and days hospitalized, with adjustment for sex, age, cancer, marital status, children, education, municipality centrality and probability of long-term NH care. We tested whether there was an effect of clustering of patients within each GP's list of patients with a random effect of GP. The intra-class correlation of patients within GP was very small [intraclass correlation coefficient 0.0014, standard error (SE) 0.0057, CI 0.0000004–0.8111]. Consequently, we used a multivariable logistic model without clustering. Unadjusted and adjusted odds ratios (OR), 95% CIs and *P*-value are reported.

We estimated associations of GP home visits (0, 1, ≥ 2), office consultations (0, 1, ≥ 2) and interdisciplinary collaboration (0, 1, ≥ 2) with number of OOH contacts and days hospitalized, separately, with negative binomial multilevel mixed-effect models. In these models, a random intercept for patients within GP was significant and included to account for clustering. Covariates were sex, age, cancer, marital status, children, education, municipality centrality, probability of long-term NH care, OOH contacts and days hospitalized. Results are presented as adjusted incidence rate ratios (IRR), CI and *P*-values. Each cause of death was not included in any regression models due to lack of convergence.

Analyses were conducted with Stata version 15 (Stata Corp, College Station, TX). Two-sided *P*-values < 0.05 were considered statistically significant in all analyses.

Results

Over 2 years, 12 136 people (15%) died at home, half in NHs and a third in hospitals (Table 1). Overall, 52% were women. In the adjusted model, women were more likely to die at home than men (OR 1.77, CI 1.66–1.89). In total, 34.7% were married. In the adjusted model, married people were less likely to die at home (OR 0.85, 95% CI 0.79–0.91). Circulatory disease (30.9%) cancer (27.2%) and respiratory disease (10.2%) were the most common causes of death. During the last 13 weeks of life 14.3% of the population received one or more home visits from their GP, 42.7% had one or more GP office consultations, 12.0% received one or more home visits from OOH services and 20.0% had one or more consultations in the OOH clinic. People were hospitalized for a median of 4 days (25th–75th percentile 0–14). Overall, 4660 GPs had 79 157 deceased people registered, meaning each GP had a median of 15 patients who died over 2 years (range 1–86, 25th–75th percentile 8–23).

Weekly contacts with GPs, OOH and hospitalizations during the last 13 weeks

The most common primary care contact type was GP office consultations, which decreased towards the end of life (Fig. 1). People who received GP home visits increased from 1% of the population in Week 13 before death to 4.6% in the last week. We found a similar development with a larger proportion of the population getting OOH home visits and consultations towards the end of life. Percentage of the population hospitalized escalated towards the end of life, with 36.8% hospitalized during the last week of life; of which 9 in 10 died in the hospital.

GP contacts during the last 4 weeks

Overall, 7442 (9.2%) patients received one or more GP home visits (range 1–28) in the last 4 weeks of life, 5051 received one (6.3%) and 2391 received two or more (3.0%) home visits. Almost a third (2.6% of all) of people who received one or more home visit died at

home, while 915 (1.1%) received two or more home visits and died at home. Another 6.5% received one or more home visits and died in a hospital (3.1%) or NH (3.4%). Furthermore, 6.6% of patients received 'appropriate follow-up' with one or more home visits when the GP had one or more interdisciplinary collaborations.

A higher proportion of cancer patients (13.9% within cancer diagnosis group) received one or more home visits than those dying from respiratory disease (10.0%), circulatory disease (7.3%) or dementia (4.2%; Fig. 2). GP office consultations were more common for people dying from circulatory disease (23.0%).

Of the 2653 people (3.3% of population) who died at home from cancer, 566 (0.7%) received one home visit and 520 (0.6%) received two or more home visits from their GP in the last 4 weeks of life. Another 10 768 people (13.3%) died in an NH from cancer; 728 (0.9%) received one GP home visit and 399 (0.5%) received two or more home visits. Additionally, 8461 (10.5%) people died from cancer in hospitals, 569 (0.7%) received one and 266 (0.3%) received two or more GP home visits.

Associations between home death and patients' contacts with GPs, OOH and hospitalizations

GP home visits were associated with dying at home compared to any other location in a dose-dependent relationship (one home visit OR 1.92, CI 1.71–2.15 and two or more OR 3.49, CI 3.08–3.96; Table 2). There was a dose-dependent association for dying at home with GP interdisciplinary collaboration. Both GP office consultations and OOH office consultations had dose-dependent association with decreased likelihood of home death. Receiving two or more OOH home visits was associated with increased odds of home death. Likewise, the odds of dying at home decreased by 5% for every day hospitalized (OR 0.95, CI 0.94–0.95). In the adjusted model, people dying from cancer were less likely to die at home than those dying from other conditions (OR 0.12, CI 0.11–0.13).

Associations between GP contacts, OOH contacts and days hospitalized

The number of GP home visits, office consultations and interdisciplinary collaborations were associated with patients having an OOH contact in a dose-dependent manner (Fig. 3). Having one or more GP office consultation or GP interdisciplinary collaboration resulted in nearly three more days hospitalized. One GP home visit increased IRR of hospitalization resulting in a 1-day increase in days hospitalized. Dying from cancer was associated with a reduction in OOH contacts (IRR 0.86, CI 0.83–0.88) and an increase in days hospitalized (IRR 1.93, CI 1.88–1.99), resulting in 6.9 more days hospitalized (CI 6.5–7.2) than people dying from other conditions.

Discussion

Main findings

Our population-based analyses showed that GP home visits and interdisciplinary collaboration increased the odds that people died at home. People leaving their home for GP consultations or OOH contacts or those who were hospitalized were less likely to die at home. Overall, 9.2% received home visits during the last 4 weeks of life, of which a third died at home. Only 6.6% additionally had GPs involved in interdisciplinary collaboration. Over a third of people were hospitalized during the last week of life. These findings are

Table 1. Characteristics and health care services in the last 13 weeks of life by place of death for all deceased people in Norway 2012–13.

	Home		Nursing home		Hospital		Other		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Total	12 136	15.0	39 349	48.7	26 920	33.3	2408	3.0	80 813	100
Sex										
Female	5166	42.6	23 907	60.8	12 604	46.8	595	24.7	42 272	52.3
Male	6970	57.4	15 442	39.2	14 316	53.2	1813	75.3	38 541	47.7
Age (median, 25th–75th percentile)	75–79	(60–64, 85–89)	85–89	(80–84, 90–94)	75–79	(65–69, 85–89)	60–64	(45–49, 75–79)	80–84	(70–74, 85–89)
Cause of death										
Cancer	2653	21.9	10 768	27.4	8461	31.4	108	4.5	21 990	27.2
Circulatory	4240	34.9	11 341	28.8	8674	32.2	721	29.9	24 976	30.9
Respiratory	967	8.0	4082	10.4	3143	11.7	68	2.8	8260	10.2
Dementia	277	2.3	4958	12.6	213	0.8	11	0.5	5459	6.8
External	1126	9.3	1201	3.1	1440	5.4	821	34.1	4588	5.7
Other	2873	23.7	6999	17.8	4989	18.5	679	28.2	15 540	19.2
Education (years)										
Primary school	5622	46.3	19 640	49.9	12 099	44.9	982	40.8	38 343	47.5
High School	4962	40.9	15 711	39.9	11 311	42.0	1004	41.7	32 988	40.8
College/university	1552	12.8	3998	10.2	3510	13.0	422	17.5	9482	11.7
Municipality centrality ^a										
Least central	1531	12.6	5132	13.0	2842	10.6	340	14.1	9845	12.2
Less central	849	7.0	2661	6.8	1834	6.8	191	7.9	5535	6.9
Somewhat central	2433	20.1	7736	19.7	4971	18.5	383	15.9	15 523	19.2
Central	7273	59.9	23 792	60.5	16 988	63.1	1409	58.5	49 462	61.2
Marital status ^b										
Not married	7797	64.3	28 214	71.7	15 291	56.8	1491	61.9	52 793	65.3
Married	4339	35.8	11 135	28.3	11 627	43.2	917	38.1	28 018	34.7
Children alive at time of death										
0	3002	24.7	7661	19.5	5015	18.6	701	29.1	16 379	20.3
1	1855	15.3	7507	19.1	4421	16.4	370	15.4	14 153	17.5
≥2	7279	60.0	24 181	61.5	17 484	65.0	1337	55.5	50 281	62.2
GP home visit										
0	9483	78.1	34 299	87.2	23 153	86.0	2321	96.4	69 256	85.7
1	1220	10.1	2994	7.6	2420	9.0	53	2.2	6687	8.3
≥2	1433	11.8	2056	5.2	1347	5.0	34	1.4	4870	6.0
GP consultation										
0	5264	43.4	29 307	74.5	10 555	39.2	1196	49.7	46 322	57.3
1	2671	22.0	4374	11.1	5553	20.6	509	21.1	13 107	16.2
≥2	4201	34.6	5668	14.4	10 812	40.2	703	29.2	21 384	26.5
GP interdisciplinary collaboration										
0	6516	53.7	24 099	61.2	15 226	56.6	2008	83.4	47 849	59.2
1	1312	10.8	4870	12.4	3713	13.8	142	5.9	10 037	12.4
≥2	4308	35.5	10 380	26.4	7981	29.7	258	10.7	22 927	28.4
Out-of-hours home visits										
0	10 952	90.2	34 420	87.5	23 428	87.0	2336	97.0	71 136	88.0
1	816	6.7	3696	9.4	2683	10.0	61	2.5	7256	9.0
≥2	368	3.0	1233	3.1	809	3.0	11	0.5	2421	3.0
Out-of-hours consultations										
0	10 166	83.8	33 178	84.3	19 187	71.3	2136	88.7	64 667	80.0
1	1513	12.5	4825	12.3	5722	21.3	186	7.7	12 246	15.2
≥2	457	3.8	1346	3.4	2011	7.5	86	3.6	3900	4.8
Days in hospital (median, 25th–75th percentile)	0.0	(0.0–5.0)	0.0	(0.0–10.0)	11.0	(4.0–22.0)	0.0	(0.0–0.0)	4.0	(0.0–14.0)

^aMunicipality centrality missing for 448 individuals.

^bMarital status missing for two individuals.

important for clinicians and policy makers. Norwegian policies are shifting towards care at home at the end of life and possibly home death, but the potential for GPs and primary care to deliver this care is currently not utilized (25,26). We need a population-based strategy for end-of-life care in primary care with a patient-centred approach (27).

Strengths and limitations

Strengths of our study are the population-based data with national coverage over 2 years. Administrative data, including remunerations from GPs and OOH services reduces self-report bias and increases completeness and validity. A large study population with little missing information provides high power. Each patient could

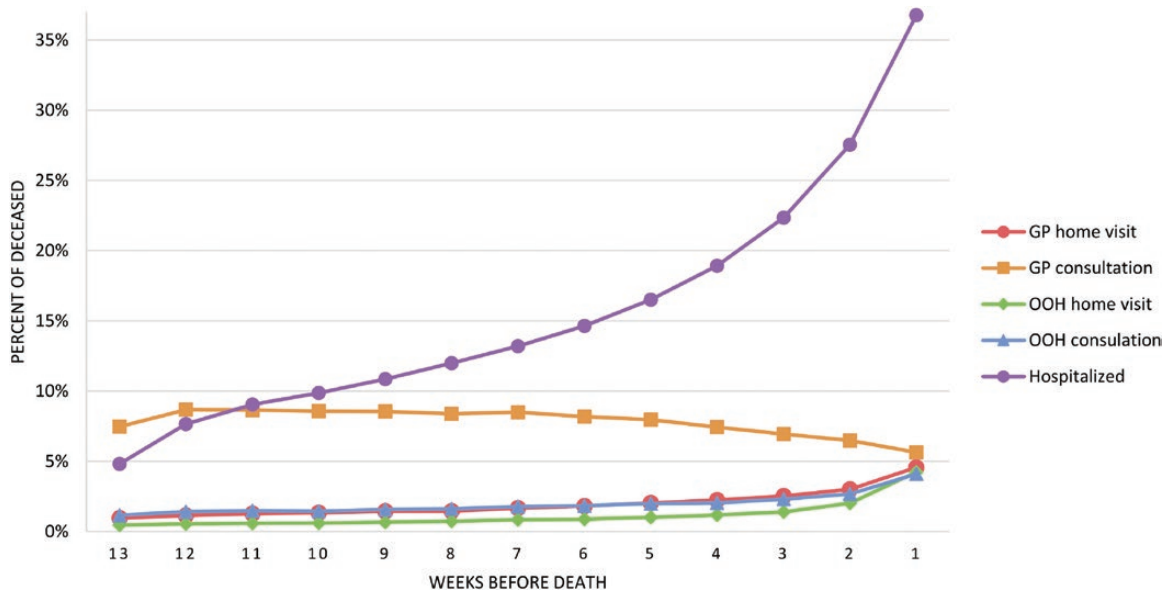


Figure 1. Percentage of all deceased with one or more of contact types: GP home visit, GP office consultation, OOH home visit, OOH consultations and/or hospitalization each week in the last 13 weeks of life.

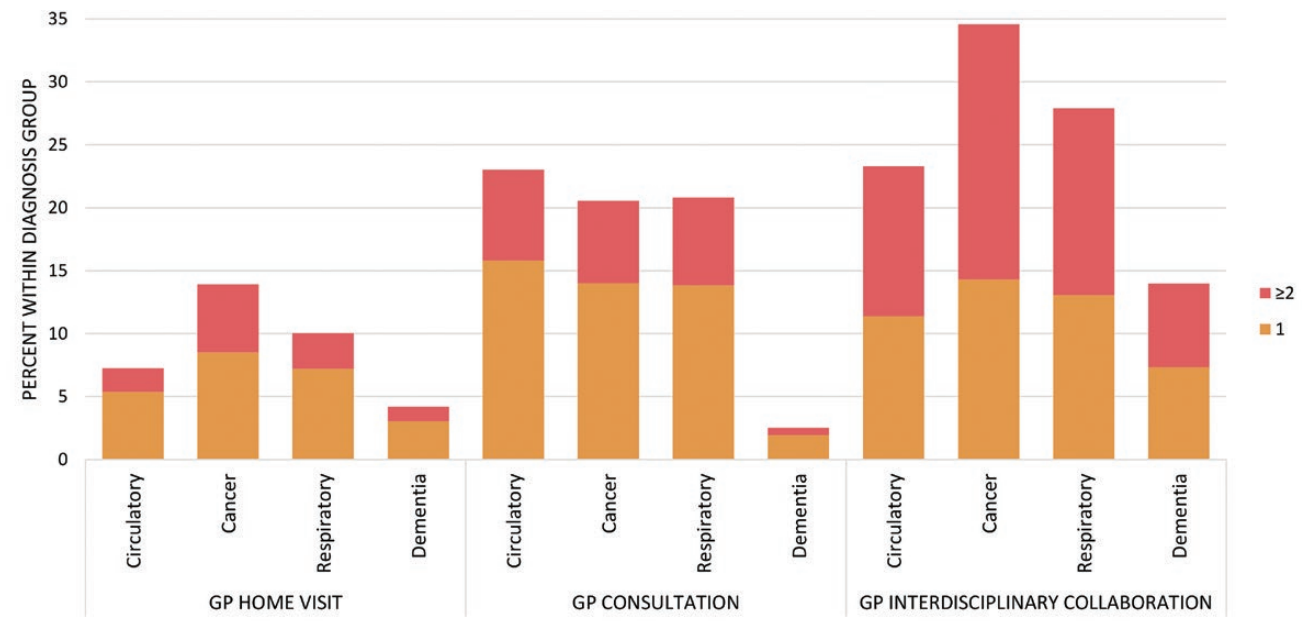


Figure 2. Percent of patients receiving GP home visits, office consultations and GP interdisciplinary collaboration in the last 4 weeks of life for the most common causes of death. Columns represent percent of patients within each of the four most common cause of death diagnosis groups.

be linked to their individual GP, thus accounting for variations explained by differences between GPs. This is the first quantification of GPs' follow-up of dying patients.

Limitations include lack of information about home nursing services and NH admissions. We partly accounted for home nursing by investigating GPs' interdisciplinary collaboration, which is predominantly with home nursing services. People with long-term NH care are retained on the GPs' patient list and were not excluded but accounted for with a prediction model for the probability of long-term care based on previous data (23,28). We could not ascertain whether OOH contacts or hospital admissions were appropriate. We could not account for outpatient specialized palliative

care. The number of hospital admissions for palliative care was negligible. Administrative data cannot investigate the quality of health care services provided to people. We controlled for some socio-demographics; other factors may influence the ability to remain at home. Our findings may be generalized to similar health care systems with GPs providing continuity of care.

Comparison with previous research

Bringing patients out of their home for health care services in the GP office, OOH clinic or hospital reduced the odds of dying at home in a dose-dependent manner. Conversely, more GP home visits and GP interdisciplinary collaboration was associated with dying at home.

Table 2. OR for home death compared to any other location of death (nursing home, hospital and other) and associations with contacts with GPs, OOH and days spent in hospital during the last 13 weeks of life for all deceased people in Norway 2012–13

	Unadjusted			Adjusted		
	OR	CI	P	Adjusted OR	CI	P
GP home visit (ref. 0)						
1	1.41	1.32–1.50	<0.001	1.92	1.71–2.15	<0.001
≥2	2.63	2.46–2.81	<0.001	3.49	3.08–3.96	<0.001
GP office consultation (ref. 0)						
1	2.00	1.90–2.10	<0.001	0.87	0.80–0.94	0.001
≥2	1.91	1.82–1.99	<0.001	0.80	0.74–0.86	<0.001
GP interdisciplinary collaboration (ref. 0)						
1	0.95	0.90–1.02	0.146	1.76	1.59–1.96	<0.001
≥2	1.47	1.41–1.53	<0.001	2.52	2.32–2.74	<0.001
Out-of-hours home visits (ref. 0)						
1	0.70	0.65–0.75	<0.001	1.04	0.92–1.17	0.553
≥2	0.99	0.88–1.10	0.793	1.26	1.03–1.54	0.024
Out-of-hours consultations (ref. 0)						
1	0.76	0.71–0.80	<0.001	0.85	0.77–0.92	<0.001
≥2	0.71	0.64–0.79	<0.001	0.78	0.67–0.90	0.001
Hospital days	0.95	0.94–0.95	<0.001	0.95	0.94–0.95	<0.001

Logistic regression with home death relative to any other location (nursing home, hospital and other) as dependent variable. Covariates adjusted for: sex, age, cancer, marital status, children, education, municipality centrality and probability of receiving long-term nursing home care. Number of observations: 80 365.

Both are associated with appropriate palliative end-of-life care from GPs (7,29) and agree with previous studies on cancer patients (2,10,16). Although home visits increased towards the end of life, in total, few dying people received this service from their GP. Previous studies have found large differences between GPs in performing home visits, with up to a quarter not involving themselves in palliative care (9,16). Reasons for not providing palliative care included not only organizational factors, such as limited resources and time, but also the GP's lack of knowledge and training in palliative care, not recognizing people needing palliative care and lack of interest or having to make home visits (8,9). GPs are required to make home visits to patients who are unable to have office consultations or to provide responsible health care according to Norwegian regulations (30). More people could benefit from follow-up from their GP at the end of life as 38–75% of dying people need palliative care (31). The UK is one of several countries with increasing number of home deaths and improved care due to systematic work to improve palliative care at all health care levels on both a population and personal level (27,32). In primary care, systematic quality improvement to enhance proactive person-centred end-of-life care by enabling earlier identification, better needs assessment, planning and coordination to meet preferences of patients nearing the end of life has led to improved outcomes (33).

Only 6.6% received appropriate GP follow-up with home visits and interdisciplinary collaboration during the last 4 weeks. We previously found that only a continuously high level of home nursing services towards the end of life was associated with people dying at home, and home nursing appeared protective of NH admission (28). Overall, 7.5% received high levels of home nursing and were estimated to have a death potentially planned to occur at home; similar to the proportion of people receiving appropriate GP follow-up (28). Key elements for staying at home appear to be continuity of care, appropriate services and interdisciplinary collaboration.

Less than 3% of people received appropriate follow-up from their GP and died at home. This is lower than previous estimations of 4.3–6.3% of dying people with home deaths potentially planned to occur at home, based on cause of death and home nursing services

(23,28), and far from the 15% who died at home. Numbers of home deaths are influenced by national policies, organization of health care services and family circumstances. It can be challenging to use home deaths as an indicator of appropriate end-of-life care. Even when end-of-life care is provided, various conditions, such as symptom burden or acute symptoms, may lead to a proper transition to another location before death (2,34). Some home deaths are sudden or unexpected and, thus, not offered palliative care.

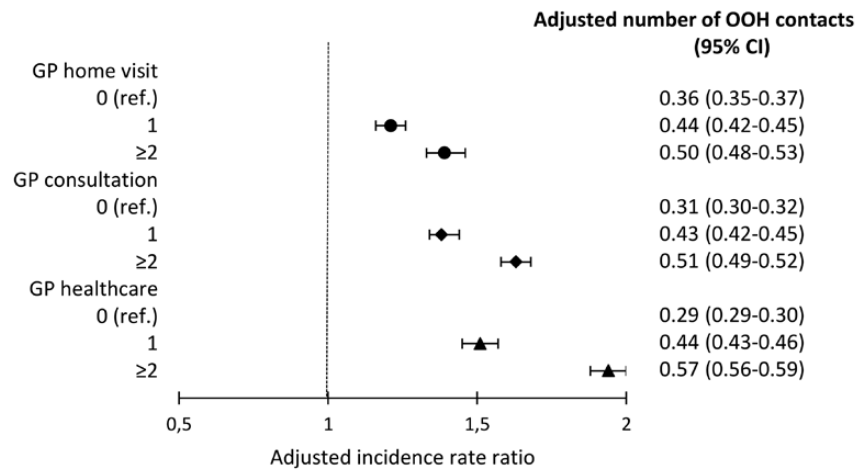
More GP contacts were associated with more OOH contacts and more days hospitalized. This could be related to patients having a high symptom burden and frequent need of health care services (2). Receiving two or more GP home visits was not associated with hospitalization length, which could indicate that a certain intensity of home visits is needed to reduce hospitalizations. A Danish study found that more home visits reduced hospitalization length for cancer patients (16). Interestingly, GPs are only involved in 26–46% of hospitalizations of patients (34,35). The rest are initiated by OOH services, patients and/or families, outpatient clinics or agreement directly with hospital wards (34,35).

Cancer patients had the highest proportion of home visits and interdisciplinary collaboration but died infrequently at home. The low proportion of cancer home deaths in Norway can be attributed to organizational factors and access to specialized palliative care in hospitals (36,37). Although primary palliative care is provided to a more diverse group (37), our results support that cancer patients receive more palliative care from GPs than organ failure patients (4). Reasons include that GPs identify patients with palliative care needs late and based on clinical judgement, leading to late initiation of palliative end-of-life care or none at all, especially for non-cancer patients (38,39).

Conclusions

GPs play an important role in enabling people to die at home by performing home visits and collaborating with other health care personnel but only for a small minority of dying people in Norway. Most people did not receive services indicating appropriate end-of-life care

A. OOH contacts



B. Hospital days

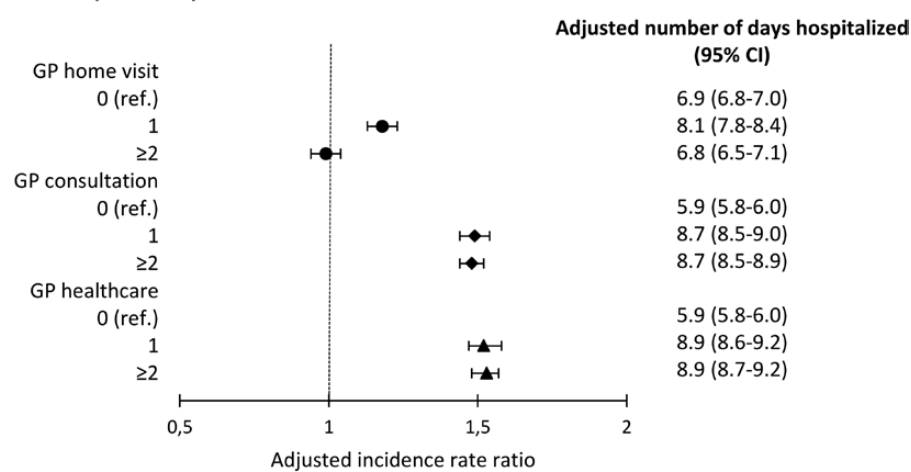


Figure 3. Associations between GP home visits, office consultations and GP interdisciplinary collaboration (GP collaboration; including telephone and interdisciplinary meetings) and (A) total number of OOH contacts and (B) total number of days hospitalized. Adjusted analyses with IRR and 95% CI error bars and adjusted absolute number of OOH contacts/days hospitalized with 95% CI.

at home from GPs. We need to investigate mechanisms behind successful follow-up from GPs at the end of life and how it can be available for more people.

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Declaration

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