Dying at home in Norway:

Health care service utilization in the final months of life

Camilla Kjellstadli

Thesis for the degree of Philosophiae Doctor (PhD)
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“Death is not the opposite of life, but a part of it.”
Haruki Murakami

Scientific environment

This research project was related to the Centre for Elderly and Nursing Home Medicine (SEFAS), Research Group for General Practice, and the Section for Elderly Medicine, Social Pharmacy and Interprofessional Workplace Learning (FEST) at the Department for Global Public Health and Primary Care (IGS), Faculty of Medicine, University of Bergen (UoB). Main supervisor was Prof. Steinar Hunskaar, Research Group for General Practice, IGS, UoB. Co supervisors were Prof. Bettina Husebo, SEFAS, IGS, UoB and Municipality of Bergen; and Assoc prof. Elisabeth Flo, Dept. Clinical Psychology, UoB.

Day to day work was conducted at SEFAS; and for six months at Yale University, School of Medicine, Department of Internal Medicine, Section of Geriatrics, Biostatistics Core under the supervision of Prof. Heather Allore.

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I have attended PhD courses at the University of Bergen, with the University of Oslo and Norwegian Medical Association. I have also participated in the Norwegian Research School for General Practice (NAFALM) and been a member of the Research School for Epidemiology (EpiNor). I participated in the 2015 Training School “Treating pain in the frail elderly with dementia” in Ghent, organized by the European COST Action TD1005. I also received a Fulbright Scholarship and travel stipends from NAFALM and UoB for a research stay at Yale University.

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Contents

Abbreviations

CI	95% Confidence Interval
EU Shortlist	European Shortlist of Causes of Death 2012
FTE	Full time equivalents
GP	General practitioner
Hrs/wk	Hours per week
ICC	Intraclass correlation
ICD-10	The International Statistical Classification of Diseases, Tenth Revision
IPLOS	The National registry for statistics on municipal healthcare services
IRR	Incidence rate ratio
KUHR	The Control and Payment of Reimbursement to Health Service Providers Database
NCoDR	The Norwegian Cause of Death Registry
NPR	The Norwegian Patient Registry
OOH	Out-of-hours
OR	Odds ratios
PPA	Posterior probability of assignment
RRR	Relative risk ratios

List of publications

Paper 1	Kjellstadli C, Husebo BS, Sandvik H, Flo E, Hunskaar S. Comparing unplanned and potentially planned home deaths: a population-based cross-sectional study. *BMC Palliative Care* 2018;17(1):69.
Paper 2	Kjellstadli C, Han L, Allore H, Flo E, Husebo E, Hunskaar S. Associations between home deaths and end of life nursing care trajectories for community-dwelling people: a population-based registry study. *BMC Health Services Research* 2019;19(1):698.
Paper 3	Kjellstadli C, Allore H, Husebo B, Flo E, Sandvik H, Hunskaar S. General practitioners' provision of end of life care and associations with dying at home: a registry-based longitudinal study. *Family Practice* 2020;cmz059.

Abstract

Background: Although many people prefer to die at home, few people die at home in Norway. We know little about sociodemographic characteristics of people who die at home, the extent of palliative end of life care provided by health care services and whether they enable people to die at home.

Aim: Investigate individual characteristics of decedents, health care service utilization in the last three months of life and associations with dying at home.

Method: Population-based registry data from the Norwegian Cause of Death Registry were linked with other Norwegian registries, covering all decedents in Norway within 2012-2013, with data from the last 13 weeks before death. Paper 1 investigated individual sociodemographic factors and estimated potentially planned home deaths that occurred at home. In Paper 2, trajectories of home nursing services and admissions to short-term skilled nursing facilities were estimated. Potentially planned home deaths for deaths in all locations were also estimated. Paper 3 investigated follow-up from general practitioners, OOH services and hospitalizations. Associations with home deaths and factors of interest were estimated by regression analyses in all papers.

Results: Overall, 15% of the total population (22% of the community-dwelling) died at home. We estimated that 24% of community-dwelling people (16% of total population) had deaths that were potentially planned to occur at home, regardless of actual location of death; nearly a third occurred at home. The most common causes of death at home were circulatory disease (35%) and cancer (22%). The predicted probability of dying at home increased with 39% when cause of death was symptoms/ill-defined and 9% for external causes of death but decreased with 12% for cancer compared to circulatory disease. In total, 18% of men and 12% of women died at home. There was a trend where younger decedents were more likely to die at home, ranging from a 39% predicted probability in people <40 years to 8% in those ≥90 years. For the community-dwelling, we estimated four trajectories of home nursing services and four short-term skilled nursing facility trajectories. Almost half received no home nursing. A quarter received a high level of home nursing; almost 7 hrs/wk. This was the only home nursing service trajectory associated with dying at home compared to hospital (aRRR 1.29). A fifth had decreasing home nursing and about 8% accelerating home nursing towards the end of life. Almost 70% had a low probability of having a short-term skilled nursing facility stay. Another 7% had intermediate probability, 16% escalating probability and 8% increasing probability of a short-term skilled nursing facility stay. Trajectories of increasing (aRRR 0.40), escalating (aRRR 0.32) and intermediate skilled nursing facility (aRRR 0.65) were associated with reduced likelihood of dying at home. Almost half the people with causes of death that predicted a potentially planned home death followed the high home nursing service trajectory. Nearly all people with potentially planned home deaths followed the trajectory with low probability of skilled nursing facility stays. During the last 13 weeks, 14% of the total population received ≥1 GP home visit, 43% ≥1 GP office consultations and 41% had GP interdisciplinary collaboration. A minority had OOH consultations, while hospitalizations escalated. During the last four weeks, 7% of patients (10% of community-dwelling) received ‘appropriate’ follow-up with ≥1 home visit when the GP had ≥1 interdisciplinary collaboration. GP home visits (1: 3%; ≥2: 7%) and interdisciplinary collaboration (1: 2%; ≥2: 5%) increased the predicted probability of dying at home in a dose-dependent manner. Health care services where the person had to leave home, including GP office consultations, OOH consultations and hospitalizations reduced the predicted probability of dying at home.

Conclusions and implications: Few people died at home and many home deaths appear to have been unplanned. At a population level, follow-up from GPs and home nursing services at the end of life may enable people to die at home. Our results imply that most people dying in Norway do not receive enough ‘appropriate’ follow-up to make a home death feasible. The potential for delivering palliative end of life care at home is not utilized. To enable more home deaths, we should start talking about our preferences regarding end of life care and place of death. The way forward must include both an individual and a system perspective to give dying people a real choice about where they spend the end of life.

Samandrag

Bakgrunn: Få personar døyr heime i Noreg, sjølv om mange ønsker å vere heime i livets slutt. Me veit lite om kven som døyr heime, omfang av lindrande behandling frå helsetenestene og om dei aukar moglegheitene for å døy heime.

Mål: Undersøke kva som karakteriserer dei døde, bruk av helsetenester i dei siste tre månader av livet og samanheng med heimedød.

Metode: Populasjonsbaserte registerdata frå Dødsårsaksregisteret blei samanstilt med data frå fleire norske register for alle døde i Noreg i 2012-2013, med informasjon frå dei siste 13 vekene av livet. Artikkel 1 undersøkte individuelle sosiodemografiske faktorar og estimerte potensielt planlagde heimedødsfall som resulterte i heimedød. I artikkel 2, blei forløp av heimesjukepleie og korttidsopphald i sjukeheim i livets slutt estimert. Potensielt planlagte heimedødsfall for alle dødsfall, uavhengig av dødsstad, blei estimert. Artikkel 3 undersøkte oppfølging frå fastlegar, legevakt og sjukehusinnleggingar. Assosiasjonar mellom heimedød og faktorar av interesse blei undersøkt med regresjonsmodellar i alle tre artiklar.

Resultat: Totalt døydde 15 % av alle personar heime (22 % av heimebuande). Me estimerte at 24% av heimebuande personar (16 % av alle døde) hadde dødsfall som potensielt var planlagt å skje heime, uavhengig av faktisk dødsstad. Nesten 1/3 døydde heime. Sirkulatorisk sjukdom (35 %) og kreft (22 %) var hyppigaste dødsårsaker heime. Predikert sannsyn for å døy heime auka med 39% når dødsårsaka var symptom/ubestemte tilstander og med 9 % for ytre årsaker, men minka med 12 % ved kreft. Til saman døydde 18 % av menn og 12 % av kvinner heime. Det var ein trend der yngre personar hadde høgare sannsyn for heimedød, frå 39% predikert sannsyn hos personar <40 år til 8 % hos dei ≥90 år. Me estimerte fire forløp av heimesjukepleie og fire forløp for korttidsopphald på sjukeheim for heimebuande personar. Om lag halvparten fekk inga heimesjukepleie. Ein fjerdedel fekk eit høgt timetal heimesjukepleie; nesten 7 timar per veke. Dette var det einaste forløpet som var assosiert med auka sannsyn for heimedød samanlikna med sjukehus (aRRR 1,29). Ein femtedel fekk minkande og rundt 8 % fekk akselererande heimesjukepleie mot slutten

av livet. Nesten 70 % hadde lågt sannsyn for korttidsopphald på sjukeheim. Vidare hadde 7 % intermediært sannsyn, 16 % eskalerande sannsyn og 8 % aukande sannsyn for korttidsopphald på sjukeheim. Forløp av aukande (aRRR 0,40), eskalerande (aRRR 0,32) og intermediært (aRRR 0,65) sannsyn for korttidsopphald sjukeheim var assosiert med redusert sannsyn for heimedød. Nesten halvparten av personar med dødsårsaker som predikerte ein potensielt planlagt heimedød fekk eit høgt timetal heimesjukepleie. Nær alle med potensielt planlagt heimedød følgde forløp med lågt sannsyn for korttidsopphald på sjukeheim. I løpet av dei siste 13 vekene fekk 14 % av pasientar ≥1 heimebesøk frå fastlegen, 43 % hadde fastlegekonsultasjonar og 41 % hadde fastlegar som deltok i interdisiplinært samarbeid. Eit mindretal hadde legevaktkonsultasjonar, mens sjukehusinnleggingar eskalerte. I løpet av dei fire siste vekene fekk 7 % av pasientar (10 % av heimebuande) 'adekvat' oppfølging med ≥1 heimebesøk frå fastlege der fastlegen også hadde ≥1 tilfelle med interdisiplinært samarbeid. Heimebesøk frå fastlege (1: 3 %; ≥2: 7 %) og interdisiplinært samarbeid (1: 2 %; ≥2: 5 %) auka predikert sannsyn for heimedød i eit doseavhengig forhold. Helsetenester der personar måtte forlate heimen, inkludert fastlegekonsultasjonar, legevaktkonsultasjonar og sjukehusinnleggingar, reduserte predikert sannsyn for heimedød.

Konklusjon og konsekvensar: Få personar døde heime og mange heimedødsfall ser ut til å ikkje ha vore planlagt. På populasjonsnivå kan oppfølging frå fastlege og heimesjukepleie i livets slutt legge til rette for meir heimedød. Våre resultat indikerer at dei fleste døyande i Noreg ikkje mottar 'adekvat' oppfølging slik at heimedød blir eit realistisk alternativ. Potensialet for å tilby lindrande behandling i livets slutt heime er ikkje utnytta. For å gjere heimedød tilgjengeleg for fleire, må me begynne å snakke om preferansar for behandling og pleie i livets slutt, inkludert preferanse for dødsstad. Vegen vidare må innehalde både eit individ- og eit systemperspektiv for å kunne tilby døyande personar eit reelt val i kvar dei ønsker å opphalde seg livets slutt.

1. Background

The population worldwide and in Norway is aging, with more people living with comorbidity and disability for an extended period of time.[1] This leads to increased care dependency in the final years of life for many. At the same time, changing family structures reduce the number of family caregivers.[2] As a consequence, health care services must provide care for more people for a longer period, including at the end of life.

As in many developed countries, dying is institutionalized in Norway.[3, 4] In 2017, 12.5% died at home, 51.9% in skilled nursing facilities and 30.3% in hospitals.[3] The proportion of home deaths in Norway is low compared to most other developed countries (Table 1).[3, 5-19]

Table 1. Percentage home deaths in developed countries.

Country	% home death	Year
Japan[1]	11	2014
Norway[1]	13	2016
Sweden[1]	18	2012
Belgium[2]	23	2007
Germany[2]	23	2011
Scotland[2]	23	2010
England[1]	24	2016
Denmark[1]	24*	2017
Switzerland[2]	27	2007-11
France[2]	28	1992-99
Singapore[2]	28	2012-15
Canada[1]	30	2004
Netherlands[1]	31	2003-06
USA[1]	31	2016

*Numbers from Denmark extracted from graph. [1]Based on total population. [2]Based on region or sample within country.

Norwegian policies, such as the Coordination reform, have given municipalities a larger role in providing health care services to its inhabitants.[20] This has led to a larger proportion of deaths taking place in skilled nursing facilities instead of hospitals in recent years, but has not led to more deaths at home (Figure 1).[3] While Belgium and Germany has had a similar development to Norway,[7, 10] Canada, the UK and the US have seen an increase in the proportion of people dying at home over the last decades.[17, 21, 22] This may be due to policies and end of life services prioritizing home deaths for people who prefer to remain at home.

Up until the start of this PhD project in 2014, limited research on palliative and end of life care in Norway was published, and there were considerable deficiencies in knowledge about both the quantity and quality of palliative care provided to community-dwelling patients.[23, 24] Additionally, the vast majority of international literature was focused on cancer patients. This background section will introduce research related to dying at home, with literature acquired throughout the research period and an updated literature search completed in January 2020 for the writing of this thesis.

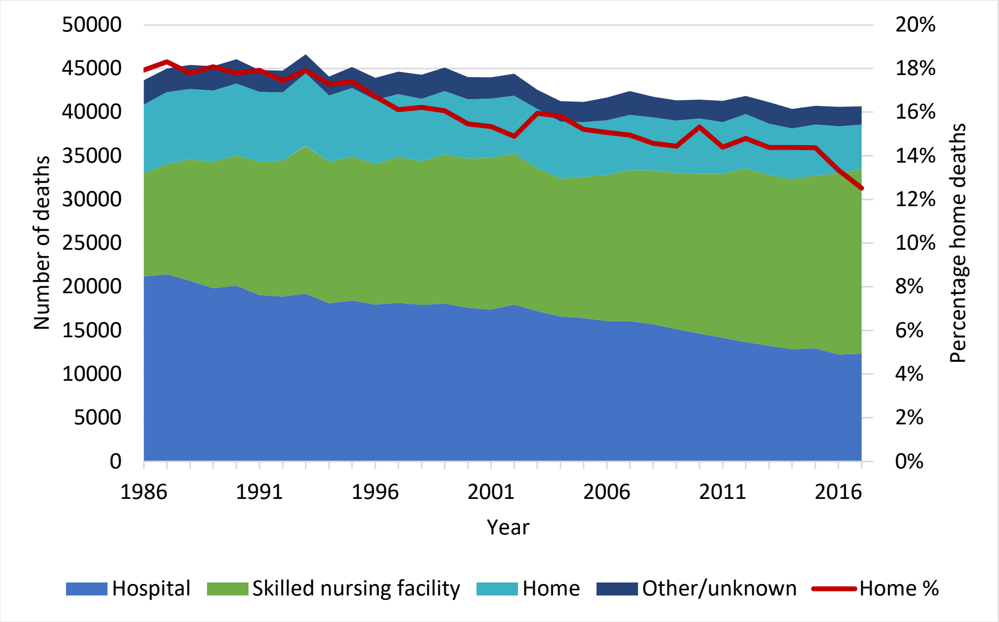


Figure 1. Place of death 1986-2017 in Norway.
Official statistics from the Norwegian Cause of Death Registry.[3] Total number of deaths by location and percentage of all deaths that occurred at home.

1.1 Dying at home

1.1.1 Preferences

Many have investigated where people prefer to die. Evidence summarized by Gomes et al. suggest that a majority of people in the general population, among patients and caregivers prefer a home death, and around 80% of patients do not change their preference for place of death with illness progression.[25] However, there were large variations depending on study population, setting and methods used; e.g. with weaker quantitative evidence for older people.[25] Qualitative research indicate that also older people prefer to remain at home, but they worry about burdening their family.[25, 26] Another review from Hoare et al. cautions that we do not know how many prefer to die at home, because of large proportions of missing data in published studies due to unreported preferences.[27]

Family caregivers are important in fulfilling a patient's preference for place of death. Fukui et al. found that adult people who were concerned about family caregiver burden and the influence of their death, were more likely to prefer institutional care to homecare.[28] Another study found that dying in a preferred location was most likely when the patient and family agreed, but was more consistent with the family's preference when they diverged for both cancer and non-cancer patients.[29] Gerber et al. investigated the decision making process when determining preferences for location of death and found that it depended on the patient and caregivers' personal history, how they dealt with uncertainty, and concerns for each other.[30] Preferences were more often conditional in favoring one place over another, but flexible in accepting that it was not always achievable.[30] To our knowledge, the preferences of the Norwegian population regarding place of care and death has not been investigated.

1.1.2 Factors associated with dying at home

Although many prefer to remain at home, this is not a realistic choice for all people who are nearing the end of life. Symptoms such as pain may become difficult to handle at home, or caregivers may become exhausted, which may lead to admission to an institution being the best option at the time.[31, 32] Both individual and system factors influence whether or not a person is able to die at home (Table 2). Whereas many individual factors are non-modifiable, system factors can be modified through changes in policies and access to health care services.

Table 2. Factors associated with dying at home

Individual	Known preference
	Advance care planning
	Family caregiver
	Caregiver coping
	Not living alone
	Ethnicity
	High socioeconomic status
	Cancer
	Low functional status
	Low comorbid disease burden
System	GP home visits
	Home nursing
	Multidisciplinary home palliative care

For people who prefer to die at home, it is important to make their preference known. Advance care planning is a repeated communication process that "enables individuals to define goals for future medical treatment and care, to discuss these goals and preferences with family and health care providers, and to record and review these preferences if appropriate".[33] A known preference for home death is associated with dying at home, and may lead to improved quality of care.[15, 34-37] Having a family caregiver and not living alone are also important elements, as both have been associated with dying at home.[34, 35] Caregiver coping is also central.[34] Other individual factors associated with dying at home include ethnicity, higher socioeconomic status, dying from cancer versus other illnesses, low functional status, lower comorbid disease burden, and living in more rural areas.[15, 34, 35] The relationship with sex and age is more unclear, with varying results from different studies.[15, 35, 38] Dying from cardiovascular disease has been associated with dying in other locations than home.[34]

System factors associated with dying at home include receiving home visits from general practitioners (GPs), home nursing services and multidisciplinary home palliative care.[34, 35, 39] On the other hand, hospital admissions in the last year of life and admission to hospitals with palliative care services is associated with dying in another location than home.[34] A Norwegian cluster randomized trial from 2000 provided a specialized palliative care intervention to cancer patients, and found that home death was more frequent in the intervention group (25%) compared to the control group (15%).[40] However, time at home did not increase, and because of a shift from skilled nursing facilities to inpatient palliative care for some patients, hospital use was unchanged.[40] Qualitative research indicates that hospitalizations at the end of life occur when end of life homecare is insufficient to meet patient needs or if the home is no longer considered to be appropriate.[41]

1.2 Palliative and end of life care

1.2.1 Definition

A core value for palliative care has been to enable people to make choices about end of life care and place of death. The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[42] Palliative care can be provided in addition to disease-modifying treatment, or become the total focus of care.[43] Usually, palliative care becomes more important with illness progression. End of life care is an important part of palliative care, and usually refers to care in the final months of life for patients with progressive disease, impaired function and increased symptom burden.[44]

1.2.2 Who needs palliative care?

A white paper from the European Association for Palliative Care, states that palliative care is appropriate for anyone living with or at risk of developing a life threatening illness, when they have unmet expectations or needs, and are willing to accept care.[43] Access should not be restricted by sex, age, diagnosis or prognosis. In a cross-national study from 12 countries, Morin et al. estimated that 38-74% of people who died were in need of palliative care.[6] While the lowest estimate excluded people with a range of chronic conditions (stroke, ischaemic heart disease, multiple scleroris, non-Alzheimer dementia and diabetes) and thus probably underestimate needs, the upper estimate gives a more inclusive estimate of palliative care needs.[6] The highest prevalence of palliative care needs were for people dying at home or in skilled nursing facilities.[6] The World Health Organization has estimated that Europe has a population of about 560 per 100,000 aged ≥15 years each year, who are in need of palliative care at the end of life.[45] This corresponds to >24,000 (60% of those who died) people aged ≥15 years in Norway in 2017 being in need of palliative care at the end of life.[45-47]

Clinical diagnosis

Traditionally, palliative care has been offered predominantly to people with cancer, but in recent years, more focus has been added on providing this service to people with chronic illnesses with limited survival, such as chronic heart failure, pulmonary, renal or neurological diseases, and dementia.[48-51] Seow et al. found that while 88% of decedents with terminal illness (cancer) received palliative care, this was only the case for 44% of patients with organ failure and 32% of people with frailty within a universal health care system (Ontario, Canada).[50] The terminal illness group also received palliative care at an earlier time and with higher intensity.[50] The disparity of people dying from other conditions than cancer in accessing palliative care, is consistently documented.[51-56]

Functional trajectories

Differences in functional decline at the end of life and how readily the end of life can be predicted, may be contributing factors to why cancer patients receive more palliative care than people dying from other conditions. Four clinical trajectories have been proposed to explain functional decline for different groups of people at the end of life: 1) sudden death, 2) terminal illness, 3) organ failure and 4) frailty.[57] Terminal illness usually refers to people dying from cancer, with a clear terminal phase. Organ failure and frailty (e.g. dementia) on the other hand have a terminal phase that is considered more difficult to predict.[58] Gill et al. however, found there was no predominant trajectory of functional decline for older people in the last year of life relating to cause of death.[59] The exception was dementia, where two thirds had persistently severe disability (similar to the frailty trajectory[57]) in the last year of life.[59]

While the trajectories using clinical conditions estimate mean trajectories for predefined groups of decedents in a hierarchal model, Gill et al. used a group-based trajectory model, where they identified the functional trajectories first and then characterized members of each trajectory with regard to causes of death. Lunney et al. compared the two methods with analyses in the same population, and confirmed that clinical conditions did not adequately predict trajectory of functional decline at the end of life.[60] While the clinical trajectories highlight that different conditions require different approaches of health care services at the end of life, trajectories of functional decline clarify that many other factors influence functional decline at the end of life.[60] Clinical condition should thus not be the only factor deciding access to palliative care.

1.2.3 Identifying people in need of palliative end of life care

Timely identification of people in need of palliative care is important to maximize benefit. There is no uniform way to objectively identify patients, and accurate prognostication is difficult.[61] Trajectories of functional decline (above) may be of limited use in individuals. General indicators, such as increase in bedrest and increase in restricting symptoms may indicate that a conversation about palliative care and end of life preferences is appropriate. Both increase substantially around five months before death for older people dying of all causes.[62, 63] Use of the *surprise questions:* “would I be surprised if this patient died within the next 6-12 months” has been proposed as a way to identify patients who might benefit from palliative care, especially in primary care by GPs. Reviews investigating the accuracy of this question alone, found large variability, with poor to modest performance in predicting death.[64, 65]

Several diagnostic tools for identifying people in need of palliative care have been developed for use in general practice.[66, 67] Many are built on each other, several include the surprise question, and all share common features such as general indicators for decline (e.g. functional status and hospital admissions) and disease specific indicators for several conditions.[66, 67] In most countries, however, identification of palliative care needs is still mostly based on the GPs clinical judgement and discharge information from secondary care.[67-69]

1.3 Palliative care in primary health care

1.3.1 Specialized and general palliative care

Palliative care can be provided at a general or a specialized level. Specialized palliative care refers to health care professionals who mainly provide palliative care; often for patients with complex problems who require other treatment options than those provided in general palliative care.[70] General palliative care is provided by health care professionals whose main focus of work is not palliative care, and requires good basic skills and knowledge in palliative care.[70]

The need for palliative care services are expected to grow due to demographic changes with aging populations and more people living with chronic diseases.[71] Although specialized community-based palliative care benefits patients and caregivers,[39, 72-74] it is unavailable for many dying people.[71, 75, 76] The need for palliative care is much larger than what specialized palliative can provide, even in high income countries.[45, 77] This has led to more emphasis on providing general palliative care in primary health care.[71, 75]

A more sustainable model is probably that most community-dwelling patients nearing the end of life receive general palliative care from GPs, home nursing services and skilled-nursing facilities, while more complex cases are referred to specialized palliative care services.[75, 77] This will require increased knowledge and skills for all involved health care personnel, improved continuity and coordination of care, and that inadequate policies and guidelines are adressed.[75, 78, 79] Gomez-Batiste et al. has provided recommendations for policy for integrated general palliative care for people with all types of chronic conditions.[80] This includes:

- Developing and implementing a systematic program with specific tools for
  - Identification
  - Assessment
  - Plan
  - Treatment
  - Evaluation
- How to address educational, organizational, and ethical challenges
- Public health policy approach
- All settings and services.

1.3.2 General practitioners

GPs may have a crucial role in providing general palliative end of life care to community-dwelling people, and increase the likelihood of their patients being able to die at home.[31, 75, 81-84] They are in a strong position to offer such services due to long-term relationships with their patients and often knowledge of the whole family and community. Patients and caregivers prefer holistic care from GPs at the end of life,[84] and more frequent GP home visits to patients at the end of life is also associated with increased caregiver satisfaction.[85]

There are also large differences between GPs in performing home visits at the end of life. Up to on-in-four do not involve themselves in palliative care at all.[86, 87] Barriers for GPs' involving themselves in of end of life care include reported lack of time, limited available resources, having to make home visits, lack of knowledge and palliative care training, lack of interest, difficulty in recognizing palliative care needs, talking to patients about end of life care, and difficulty in predicting time of death.[83, 87-91] However, programs for systematic quality improvement to enhance person-centered end of life care in primary care are being implemented for example in the UK and has led to improved outcomes for patients and caregivers.[92]

Most research to date has been using self-report from GPs or mainly focused on cancer patients.[31, 76, 83-86, 93-96] There is little knowledge on Norwegian GPs' contribution to end of life care for their patients, and if the same mechanisms are working here.

1.3.3 Home nursing services

Nurses constitute the largest group of health care professionals, but there is little research on whether home care nurses (district nurses) provide general palliative end of life care to community-dwelling patients, and if so, how they do it. Most of the available studies are qualitative with small sample sizes which capture what the nurses say they do, but not what they actually do, or how they impact outcomes.[97, 98] A Canadian study of cancer patients found that home nursing was protective of hospitalization and emergency department visits in the last month of life, and end of life home nursing with an end of life intent (more resources) provided by regular home nurses, was protective in the last six months of life.[99, 100] Home nurses may be the health care professionals who see the patient most often, and have a unique opportunity to care for patients also at the end of life.

1.4 Organization of palliative end of life care in Norway

1.4.1 The Norwegian health care system

Norway has universal health care. Municipalities are required to offer health care services to its inhabitants and ensure that all have access to a GP and primary out-of-hours (OOH) services. The central government is responsible for providing hospital services.

Municipal health care services are based on needs, and offered to almost 7% of the population.[101] This includes practical help in daily tasks, personal assistance, daycare, food delivery, personal safety alarm, home nursing, rehabilitation facilities, short-term and long-term skilled nursing facilities, but does not include GP or OOH services. Services are expanding due to increased longevity and more people requiring assistance with increasing age. In 2016, 47,647 people received long-term skilled nursing facility care, 67,430 received short-term skilled nursing facility care, and 223,780 received home nursing.[101] More than half (55%) of those who receive home nursing are living alone.[24]

Skilled nursing facilities have a deductible based on income, while home nursing services are free to the patient. GPs and outpatient clinics offer services for a fee, up to a maximum expenditure per year, currently 2085-2369 NOK (approximately 250 EUR).[102] Hospitalizations are free to the patient.

Palliative care is organized into general and specialized palliative care (Figure 2). There is no medical specialization in palliative care, but around 65 physicians located both in primary and secondary health care have a certified palliative medicine special area of competence.[103] Specialized palliative care is mainly provided to cancer patients both in hospitals and municipalities.[48] Guidelines for palliative care are predominantly focused on cancer patients, except for a pediatric guideline for palliative care regardless of diagnosis.[24, 48]

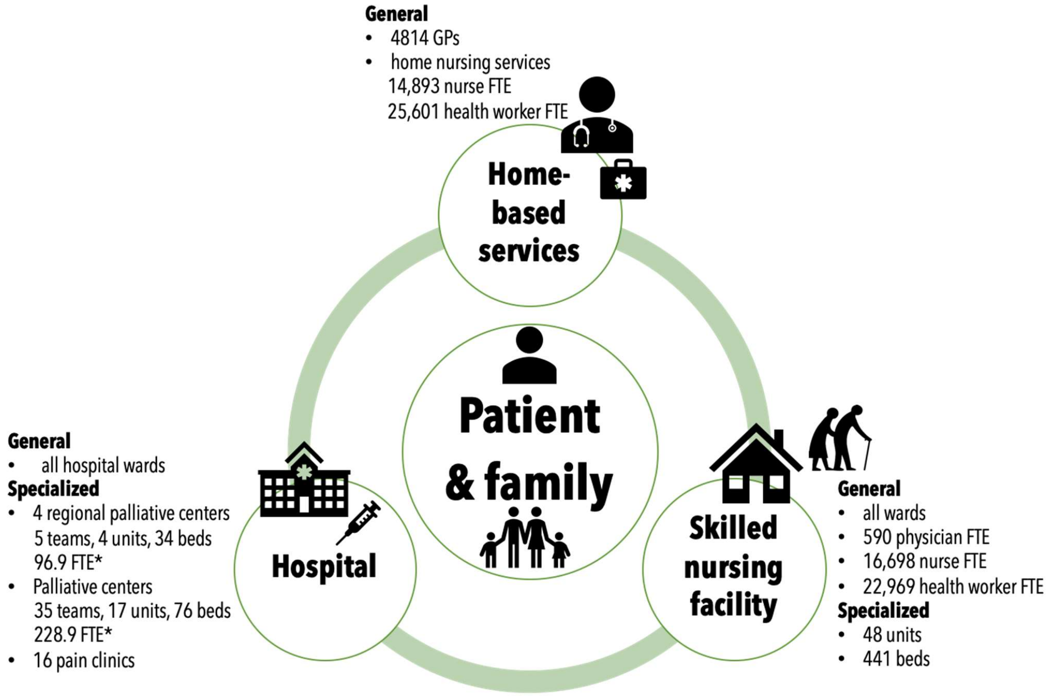


Figure 2. Palliative care services in Norway.[24, 43, 104-106]
Abbreviations: FTE: Full time equivalents. GP: General practitioner. *Refers to all staff.

1.4.2 Hospitals

Hospital wards offer general palliative care to admitted patients. Specialized palliative care is provided in palliative centers with palliative inpatient units and/or outpatient clinics organized at a local or regional level; of which some provide home visits. Regional centers also work with research and development. Pain clinics may offer specialized pain treatment to palliative patients.[24] Pediatric patients are mainly treated within pediatric units, where palliative care is focused on children with cancer.[48]

1.4.3 Skilled nursing facilities

All skilled nursing facilities offer general palliative care, and some also specialized palliative care. There were 48 palliative units within skilled nursing facilities in 2017 with a total of 294 beds, and an additional 147 single palliative beds within regular skilled nursing facilities.[24] Palliative units consist of ≥4 beds, they have more staff and a physician with competency in palliative care.[24]

1.4.4 Home

Community-dwelling people receive care from home nursing services, GPs and other municipal health care personnel in addition to family caregivers.

Home nursing services

Home nursing services offer general palliative care. Around 25% of workers are unskilled.[107] Half of all municipalities have a cancer/palliative coordinator who work to improve care coordination and quality of life for community-dwelling patients with cancer and their caregivers.[24, 48] There are no municipal specialized palliative teams, except one non-profit organization in Oslo (Fransiskushjelpen), which cares for community-dwelling cancer patients.[24]

General practitioners

There are around 4800 GPs in Norway.[105] Almost all Norwegian citizens (99.8%) are registered with a GP.[105] They offer continuity of care with long-term relationships and services during daytime and OHH.[108] Reports about the GPs' involvement in palliative care is variable, but indicate that more involvement in palliative patients may be necessary.[24, 48] The GP is required to perform home visits to patients who are unable to come to the GP clinic for consultations or when it is necessary to provide responsible health care.[109] However, the number of home visits have decreased after 2012 (95 per 1000 inhabitants in 2016), except for people ≥90 years.[110] In general, home visits are mainly provided to the oldest population and in municipalities with <20,000 inhabitants.[110] Number of contacts for interdisciplinary collaboration increased until 2014, before it started declining (97 per 1000 inhabitants in 2016).[110]

Family caregivers

Family caregivers are considered essential for persons who prefer to remain at home at the end of life. It is estimated that family caregivers' care contribution (in all areas) equals around 100,000 full time equivalents.[111] Unfortunately, the interaction between family caregivers and official health care services is often random or lacking.[111] Elderly people mainly receive care from official health care services and their spouse or partner, rather than their children.[111] Family caregivers who want to care for a family member in the final stages of life, may receive compensation in form of an attendance allowance from the government.[112] The allowance is limited to 60 days for each person nearing the end of life and can be divided between several family caregivers.

1.5 Rationale of the thesis

Dying at home is a complex issue, and dependent on many elements being in place at the right time. Studies from other countries are not necessarily generalizable to Norway, due to differences in culture, society and health care system. Some knowledge about specialized palliative care has been reported previously from Norway, but little is known about who dies at home and how primary health care services provide palliative end of life care to the population. Many individual factors are non-modifiable, whereas system factors are modifiable through changes in policies and organization of health care services. Before we can improve services, we need knowledge about the services actually offered, both quantity and quality, and on both an individual and a population level.

2. Aims of the thesis

The overall aim of this thesis is to investigate individual characteristics of decedents, health care service utilization in the last months before death and associations with dying at home within the context of the Norwegian health care system. Registry data provides a population-based perspective on patterns of service utilization and individual characteristics of decedents. The three papers included in this thesis cover different aspects and contribute to the overall aim:

Paper 1

This paper aims to:

- Investigate factors associated with dying at home compared to other locations
- Estimate how many home deaths that may have been planned to occur at home
- Investigate individual differences between people with potentially planned home deaths and where a home death appears not to have been planned

Paper 2

This paper aims to:

- Investigate trajectories of nursing services in the last 13 weeks of life
- Estimate how many deaths that potentially could have been planned to occur at home, regardless of actual place of death
- Investigate associations between place of death, potentially planned home deaths and nursing service trajectories

Paper 3

This paper aims to:

- Investigate patterns of patients' contacts with GPs, primary care OOH services and hospitalizations in the last 13 weeks of life

- Investigate whether patients' contacts with GPs (office consultations, home visits), GPs interdisciplinary collaboration, primary care OOH contacts and hospitalizations in the last 13 weeks of life were associated with dying at home
- Investigate whether various GP contacts were associated with fewer OOH contacts or days hospitalized during the last 13 weeks of life

3. Materials and methods

3.1 Data sources

3.1.1 The Norwegian Cause of Death Registry

The Norwegian Cause of Death Registry (NCoDR) records and produce national statistics on all deaths. NCoDR records cause of death and place of death for all Norwegian residents living in Norway or abroad, and all non-residents living in Norway.[113, 114] Death certificates are completed by the physician who has examined the deceased person; usually the treating physician or an OOH duty physician. The death certificate goes through the local county court or police to the Chief municipal medical officer, before reaching the registry. NCoDR has a high degree of coverage and completeness, with medical information on >98% of all deaths. Two quality assessments have ranked NCoDR in the second-best group with "medium" and "medium-high" quality respectively, and one in the best-quality group. Use of unspecific codes lowered the score in all three assessments. Few validation studies have been conducted.[113] Until 2014, Statistics Norway was responsible for the registry, when the Norwegian Institute of Public Health was given full responsibility.[113] Information from NCoDR was used in all three papers.

3.1.2 The National Registry for Statistics on Municipal Health Care Services

The National Registry for Statistics on Municipal Health Care Services (IPLOS) is a registry for statistics on municipal health care services administered by the Norwegian Directorate of Health.[115] Since 2007 it has been the main data source for Norwegian municipal health care statistics. It is a pseudonymous register where service recipients can be followed over time without recognizing the specific individual. Exemptions for linkage with other data can be made, when the data provided to researchers remain anonymous. IPLOS has compulsory registration for all municipalities on all persons who apply for or receive municipal health care services. They register the person's resources, need of assistance and services provided. The information is generated from the journal and archiving systems which are in everyday use in the municipalities and does not require additional reporting. Data quality is assessed by comparison with information from other official statistics (KOSTRA – Municipality-State-Reporting) and reports are returned to the municipalities.[101, 116] An internal quality assessment of the 2012 data registered in IPLOS shows few registration errors in measures included in this study.[117] A research project to validate IPLOS regarding community-dwelling persons with cognitive impairment, found that IPLOS was well suited for assessing needs relating to activities of daily living, but less so when considering cognitive function.[118] Information from IPLOS was used in **Paper 1** and **Paper 2**.

3.1.3 The Control and Payment of Reimbursement to Health Service Providers Database

The Control and Payment of Reimbursement to Health Service Providers Database (KUHR) is owned by the Norwegian Directorate of Health. It is an administrative database that handles reimbursements from the Norwegian government to GPs, OOH physicians, other health care professionals and institutions.[119] The database includes electronic billing claims, which make up >99% of all claims and is a reliable source.[120] Information reflects utilization of the above mentioned health care services in the population. One billing claim is made for every contact, and identifies contact type, the physician, the patient, diagnoses and specific fee codes. Information about the GPs from the General Practitioner Register was also provided by the Norwegian Directorate of Health, which allowed linkage between the GP and their registered patients. Information about GP and OOH contacts from the KUHR database was used in **Paper 3**.

3.1.4 The Norwegian Patient Registry

The Norwegian Patient Registry (NPR) is administered by the Norwegian Directorate of Health and contains data from the specialist health care services. This includes information on persons waiting on or who have received treatment in hospitals, outpatient clinics or from private specialist practitioners.[121] Data completeness in reporting personal identification number for patients is mostly high with a few exceptions, while knowledge about data quality is not sufficiently reported.[122] Information from areas with low completeness (private specialist practitioners, newborns in some health care regions) was not used in this project. Information from NPR was used in **Paper 3**.

3.1.5 Statistics Norway

Statistics Norway is an independent institution responsible for collecting and publishing official statistics about the Norwegian society, economy and population. Data come from several sources with yearly updates. They provide statistical data from several areas to researchers, such as family relationships, marital status, citizenship, place of residence and educational level.[123] Statistics Norway work systematically with quality.[124] We used data from Statistics Norway in **Paper 3**.

3.2 Study population and design

All three papers are based on individually linked data on all deceased individuals in Norway from 1 January 2012 to 31 December 2013. Information about sociodemographic data and health care utilization for each day of the last 13 weeks (3 months) of life was collected retrospectively. An overview of data sources is given in Table 3.

Table 3. Overview of studies, papers and registries/databases

	Design	**NCoDR**	**IPLOS**	**KUHR**	**NPR**	**Statistics Norway**
Paper 1	Cross-sectional	X	X			
Paper 2	Longitudinal	X	X			
Paper 3	Longitudinal	X	(X)	X	X	X

NCoDR: The Norwegian Cause of Death Registry. IPLOS: The National Registry for Statistics on Municipal Health Care Services. KUHR: The Control and Payment of Reimbursement to Health Service Providers Database. NPR: The Norwegian Patient Registry.

In **Paper 1** we used a cross-sectional design. The study population consisted of all 80,908 deceased people, excluding those with missing information about place of death (n=2521) or sex (n=5). **Paper 2** had a longitudinal design and included all 53,396 deceased community-dwelling people, excluding those with missing information about place of death (n=2521), sex (n=5) or who had a decision of long-term skilled nursing facility care (n=27,512). Day of death was set as day zero, and all events decremented for each day of the last 13 weeks. We used a longitudinal design in **Paper 3**. The study population consisted of all 80,813 deceased people. We excluded those with missing information about patient identification number (n=135), place of death (n=2484), or where country of residence was not Norway (n=15). All events were decremented each day from the day of death for 13 weeks.

3.3 Measures

Place of death

Place of death was provided by NCoDR and a main outcome and grouping variable in all three papers. We categorized place of death into four categories: home, skilled nursing facility (long-term and short-term), hospital, and other location (abroad, under transportation to hospital, other). All three papers used this categorization for descriptive results. In **Paper 1**, we compared deaths at home, skilled nursing facilities and hospitals. **Paper 2** used place of death as an outcome with four categories (above). Only short-term skilled nursing facility stays were used due to study inclusion criteria. In **Paper 3,** place of death was dichotomized into home and any other locations (skilled nursing facility, hospital, other).

Potentially planned home deaths

Although registry data cannot be used to estimate people's preference for dying at home, we can differentiate sudden, unplanned home deaths from those where health care service utilization implied that resources were allocated to facilitate time at home. We can also differentiate people with causes of death that are known to have a higher probability of receiving palliative care and might accordingly focus on more time spent at home or a plan to die at home.[48] Potentially planned home deaths were estimated based on information about municipal health care services (IPLOS) and cause of death (NCoDR), with slightly different criteria in **Paper 1** and **Paper 2**.

Paper 1 – Estimate 1

A home death was considered potentially planned to occur at home if a person received domiciliary care (municipal home nursing services or practical home-based services) at any time during the last 13 weeks of life *and* had a cause of death among those most likely to receive palliative care (Figure 3). These were according to the European Shortlist for Causes of Death: Cancer (2.), Circulatory disease (7.), Respiratory disease (8.), Kidney disease (12.1) and Neurological disease (6.1, 6.3).[48, 125] Dementia was not included in this group because almost everyone with dementia in Norway die in skilled nursing facilities.[126] The remaining home deaths were categorized as unplanned to occur at home.

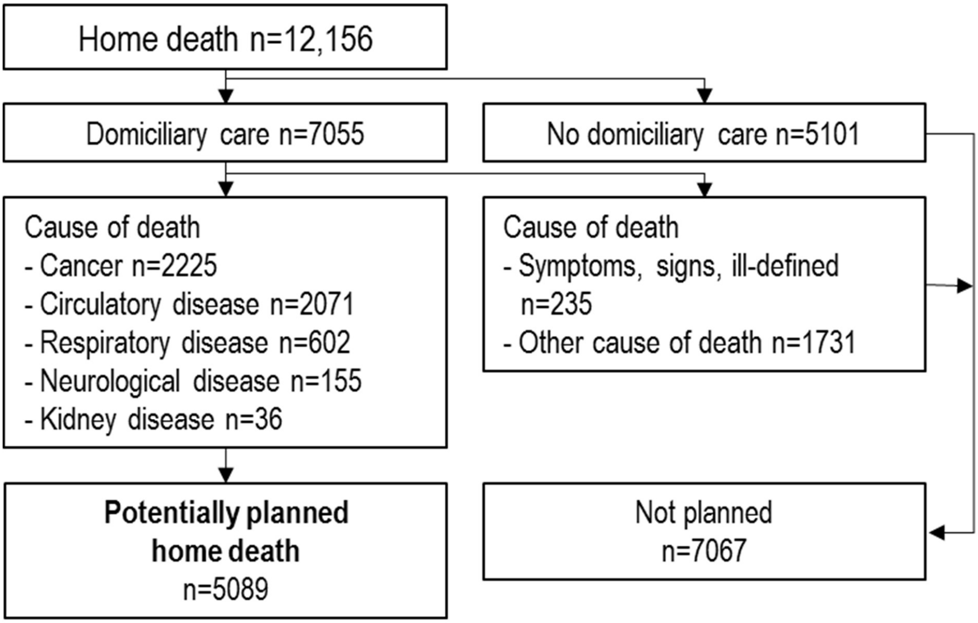


Figure 3. Estimation of potentially planned home deaths used in Paper 1. Algorithm for estimating potentially planned and unplanned home deaths among people who died at home.

Paper 2 – Estimate 2

Although a person may have had a plan to remain at home towards the end of life or die at home, this does not necessarily end up transpiring, due to various circumstances. To account for this, we expanded the definition of potentially planned home deaths to also include deaths that occurred in other locations (Figure 4). People in long-term care were considered highly unlikely to have a plan to die at home and excluded. We used a narrower definition of diagnoses most likely to receive palliative care. According to the European Shortlist for Causes of Death, this was Cancer (2.), Heart disease (7./7.1.2/7.2/7.4; excluding acute myocardial infarction), Chronic pulmonary disease (8./8.3/8.3.1/8.3.2/8.4), Kidney disease (12.1) or Neurological disease (6./6.1/6.3).[48, 125] Receiving home nursing seven days before death was defined as the latest time of initiation of services compatible with receiving palliative end of life care at home.

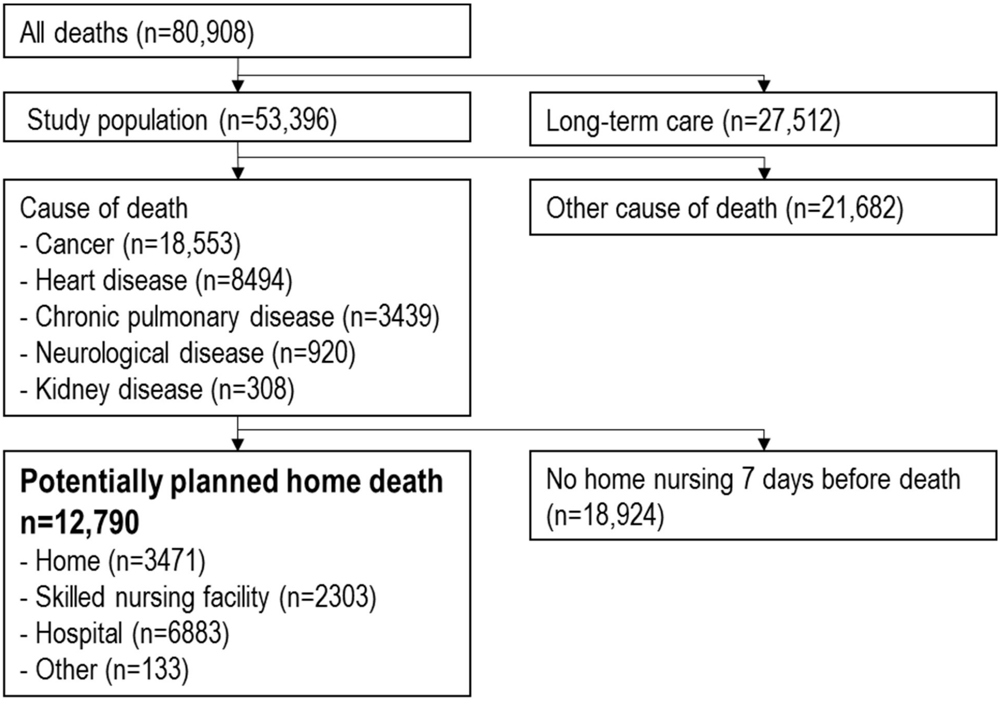


Figure 4. Estimation of potentially planned home deaths used in Paper 2.
Algorithm for estimating potentially planned and unplanned home deaths among all community-dwelling people, regardless of actual place of death.

Municipal nursing services

Information about municipal nursing services was based on service decisions provided by IPLOS and used in **Paper 1** and **Paper 2**.

In **Paper 1**, we defined *domiciliary care* as receiving municipal home nursing services or practical home-based services at any time during the last 13 weeks or not. *Skilled nursing facility stays* included both short-term and long-term stays and were defined as ‘yes’ for anyone having a stay of any duration during the last 13 weeks, else ‘no’. Domiciliary care and skilled nursing facility stays were used as covariates. In **Paper 2**, *home nursing services* were estimated as mean hours per week (hrs/wk) for each of the 13 weeks leading up to death and based on service decisions. Minimum value was zero hrs/wk for people who did not receive any home nursing in a particular week. Maximum value was set to 168 hrs/wk, which indicated a person received care around the clock. *Short-term skilled nursing facility stays* were classified as occurring or not for each of the thirteen weeks leading up to death.

Contacts with general practitioners

Information about contacts with GPs were provided by the KUHR database and used in **Paper 3**. We included 253,663 billing claims from GPs that were home visits or office consultations with patients, or contacts with other health care personnel regarding the patient during the last 13 weeks of life. GP contacts with other health care personnel is mainly with home nurses. We used it as an indicator of interdisciplinary collaboration, and as meaning that different health care professionals work together to achieve better patient care. Each contact type was used as a continuous variable and a categorical variable with counts per contact type (0, 1 or ≥2). We defined receiving ≥1 GP home visit and ≥1 GP interdisciplinary collaboration as ‘appropriate’ follow-up at the end of life.

Contacts with primary care out-of-hours services

Contacts with primary care OOH services were provided by the KUHR database and used in **Paper 3**. We included 53,703 billing claims that were physician home visits or office consultations with patients during the last 13 weeks of life. Each contact type was used as a continuous variable and a categorical variable with counts per contact type (0, 1 or ≥2).

Hospitalizations

Information about hospitalizations was provided by NPR and used in **Paper 3**. In total, 45 hospital admissions were excluded because they were coded as starting after death. Discharge date was set to the day of death for 3923 hospital admissions coded as discharge after death. Hospitalization was used as a continuous variable counting total number of days spent in hospital during the last 13 weeks of life.

Covariates

Based on previous knowledge from other countries,[35, 127-130] we selected relevant factors in relation to cause of death that was available in the registries and databases utilized.

Table 4. Causes of death used in each of the three papers

	Code	Diagnoses
Paper 1	EU shortlist	Infectious/parasitic (1.) Symptoms/signs/ill-defined (16.) External (17.) Cancer (2.) Dementia (5.1, 6.2) Circulatory (7.) Respiratory (8.) Other (specified).
Paper 2	EU shortlist	Cancer (2.) Heart (7./7.1.2/7.2/7.4) Chronic pulmonary (8.0/8.3/8.3.1/8.3.2/8.4) Kidney (12.1) Neurological (6.0/6.1/6.3) Other (specified).
Paper 3	ICD-10	Cancer (C00-D49) Circulatory (I00-I99) Respiratory (J00-J99) Dementia (F00-F03, G30) External (V00-Y99) Other (specified).

EU Shortlist: European Shortlist for Causes of Death.[125] ICD-10: The International Statistical Classification of Diseases, Tenth Revision.[131] Codes in parenthesis refer to specific codes within the Classifications.

Cause of death was provided by NCoDR (Table 4). Cause of death was missing for 242 individuals in **Paper 3** and coded into ‘other’. Whether cancer was cause of death were used in regression analyses instead of all causes of death in **Paper 3**.

Sex was provided by NCoDR and coded as male or female. *Age* was provided by NCoDR. In **Paper 1** and **Paper 2** age at time of death was divided into seven groups: 0–39, 40–49, 50–59, 60–69, 70–79, 80– 89, ≥90 years. In **Paper 3** age at time of death was given in 5-year intervals up to 104, then ≥105.

Statistics Norway provided information about *municipality population* and *centrality*. Municipality population was missing for 285 individuals. It was classified as 0-2000; 2001-5000; 5001-10,000; 10,001-50,000 and ≥50,001 and used in **Paper 1**. Municipality centrality was used in all three papers, and refers to a municipality’s geographic location in relation to a center with important functions, where 0 is least central (rural) and 3 is most central (urban).[132] Municipality centrality was missing for 285 individuals in **Paper 1** and **2**, and for 448 individuals in **Paper 3**.

Statistics Norway provided information about *education*, which was used in **Paper 3**. Education specified highest completed education level: primary school, high school or college/university. An unknown education level was categorized as primary school (n=1422, 2.4%).

In **Paper 1** and **Paper 2**, IPLOS provided information about *household*, which was categorized as cohabiting or living alone. IPLOS coded people living in assisted living accommodation with separate apartments as living alone, while those living in long-term skilled nursing facilities were coded as cohabiting.[116] This variable was only available for the people registered in IPLOS and thus received municipal care, and was in total missing for 18,478 individuals. Statistics Norway provided information about *marital status* in **Paper 3.** Marital status was missing for 2 individuals. We defined marital status as ‘not married’ if a person was unmarried, widowed, divorced, separated, separated partner, divorced partner or surviving partner, and ‘married’ if a person was married or a registered partner at time of death. Number of living *children* of the deceased at time of death was provided by Statistics Norway and categorized as 0, 1 or ≥2. This covariate was used in **Paper 3**.

3.4 Statistical analyses

Descriptive statistics in relation to place of death were used in all three papers. Categorical variables were evaluated with Pearson Chi Square tests. Continuous variables were evaluated with median and 25th-75th percentiles. All three papers investigated factors associated with place of death in regression analyses. Marginal standardization (Stata *margins* and *margins plot*), which calculate absolute effects as predicted probabilities and differences in predicted probabilities of dying at home, are reported for regressions analyses results in the thesis which are not reported in the papers.[133] Significance was accepted at the 5% level ($p < 0.05$) for all analyses in all three papers. All statistical analyses were conducted with STATA version 14 (**Paper 1**) and version 15 (**Paper 2** and **Paper 3**) (Stata Corp, College Station, TX).

Paper 1

Multinomial logistic regression was used to assess associations between place of death and sex, age, cause of death, municipality population, municipality centrality and domiciliary care. We repeated the analysis in the subpopulation of people who were registered in IPLOS to include type of household as covariate. Estimates were given as adjusted relative risk ratios (aRRR) with 95% confidence intervals (CI) and p-values. Logistic regression investigated differences between people with potentially planned home deaths versus unplanned home deaths in two separate models. In model 1, we adjusted for sex, age, municipality population, municipality centrality and skilled nursing facility. In model 2, we also adjusted for household in the population who were registered in IPLOS. Estimates were presented as unadjusted and adjusted odds ratios (OR) with CI and p-values.

Paper 2

We modeled development of home nursing services and short-term skilled nursing facility stays in the last 13 weeks of life simultaneously with a group-based dual-trajectory model using a Stata Traj plugin.[134, 135] Group-based trajectory modeling is a semiparametric finite mixture model for longitudinal data using a maximum likelihood method.[135] We used a censored normal distribution to model home nursing hrs/wk. The outcome was log transformed to normalize ($\log_{10}$(home nursing hrs/wk +0.1)). Short-term skilled nursing facility stays were modeled as the probability of being in a short-term skilled nursing facility each of the 13 weeks leading up to death with a Bernoulli distribution. Each outcome was modeled separately, then jointly. Model selection was done by adding one trajectory at a time followed by varying higher-order growth terms until an optimal fit was achieved. Optimal fit was evaluated by the Bayesian Information Criterion, average posterior probability of assignment (PPA) (≥ 0.9 considered excellent fit), odds of correct classification, the proportion with PPA<0.7 (indicated poor fit), and differences between predicted and observed group proportions.[135] For meaningful interpretation, a group size of 5% of the population was considered a minimum.

We used multinomial logistic regression to assess place of death and associations with potentially planned home deaths, trajectories of home nursing services and short-term skilled nursing facility stays. We adjusted for sex, age and municipality centrality. We repeated the analysis in the population registered in IPLOS to assess household as a possible confounder, without any indication of this being the case. Results were presented as aRRR with CI and p-values.

Paper 3

People receiving long-term skilled nursing facility care receive follow-up from nursing home physicians instead of their personal GP. Although they are not exposed to GP care, they remain on their personal GPs´ patients list. We generated the probability of being in long-term skilled nursing facility care with data from IPLOS and NCoDR, to account for people not exposed to GP care. Factors available in both datasets: age, sex, place of death, cause of death main categories by European Shortlist for Causes of Death,[125] death certificate, death abroad, special circumstances, autopsy, and police report were used in the model after a stepwise backward selection. The model had excellent fit and prediction (receiver operating characteristic area 0.901 (CI 0.898-

0.903)). We then used this predicted probability as a propensity score covariate in the models using the NCoDR/NPR/Statistics Norway/KUHR dataset.

We used logistic regression to analyze associations between place of death (dying at home versus any other location) and factors of interest: number of GP home visits (0, 1, or ≥2), number of GP consultations (0, 1, or ≥2), number of GPs contact with other health care services (0, 1, or ≥2), number of OOH home visits (0, 1, or ≥2), number of OOH consultations (0, 1, or ≥2) and days hospitalized. We adjusted for sex, age, whether cancer was cause of death, marital status, children, education, municipality centrality and probability of long-term skilled nursing facility care. We tested whether there was an effect of clustering of patients within GP by having a random effect of GP, but the intraclass correlation (ICC) of patients within GP was very small (ICC 0.0014, SE 0.0057, CI 0.0000004-0.8111). Accordingly, we used a logistic regression model without clustering for GP with results presented as unadjusted and adjusted OR, CI and p-values. We used negative binomial multilevel mixed-effects analyzes in two separate models to estimate the association of GP home visits (0, 1, or ≥2), GP office consultations (0, 1, or ≥2) and GP interdisciplinary collaboration (0, 1, or ≥2) with number of OOH contacts (outcome 1) and days hospitalized (outcome 2). A random intercept for patients within GP was significant and included to account for clustering in both models. Covariates were sex, age, whether cancer was cause of death, marital status, children, education, municipality centrality, probability of being long-term in a skilled nursing facility and days hospitalized (model 1) or OOH contacts (model 2). Estimates were presented as adjusted incidence rate ratios (IRR) with CI, p-values, adjusted absolute numbers of OOH contacts and adjusted absolute number of days hospitalized. Due to lack of convergence, each cause of death was not included in any of the regression models.

3.5 Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics North (2014/2308) and the Norwegian Data Protection Authority (15/00450-2/CGN, 17/00341-3/SBO). Approvals for registry data and linkage were given by the responsible authorities: the Norwegian Institute of Public Health (NCoDR), the Norwegian Directorate of Health (KUHR, NPR, and IPLOS) and Statistics Norway. A trusted third party performed linkage of data. Statistics Norway linked data from NCoDR and IPLOS and delivered anonymous data. The Norwegian Prescription Database[136] linked data from NCoDR, KUHR, Statistics Norway and NPR and provided indirectly identifiable data to the researchers. Societal benefits were evaluated to outweigh potential risks. Informed consent was not possible.

4. Main results

4.1 Paper 1

Over two years, 15.0% of the population died at home, 48.6% died in skilled nursing facilities, 33.3% in hospitals and 3.0% in other locations. In total, 12.2% of all women and 18.1% of all men died at home. Men had a 16.7% (CI 16.4, 17.1) predicted probability of dying at home in adjusted analyses, 2.4% (CI -3.0, -1.9) higher than women. There was a trend that predicted probability of dying at home decreased with increasing age (Figure 5).

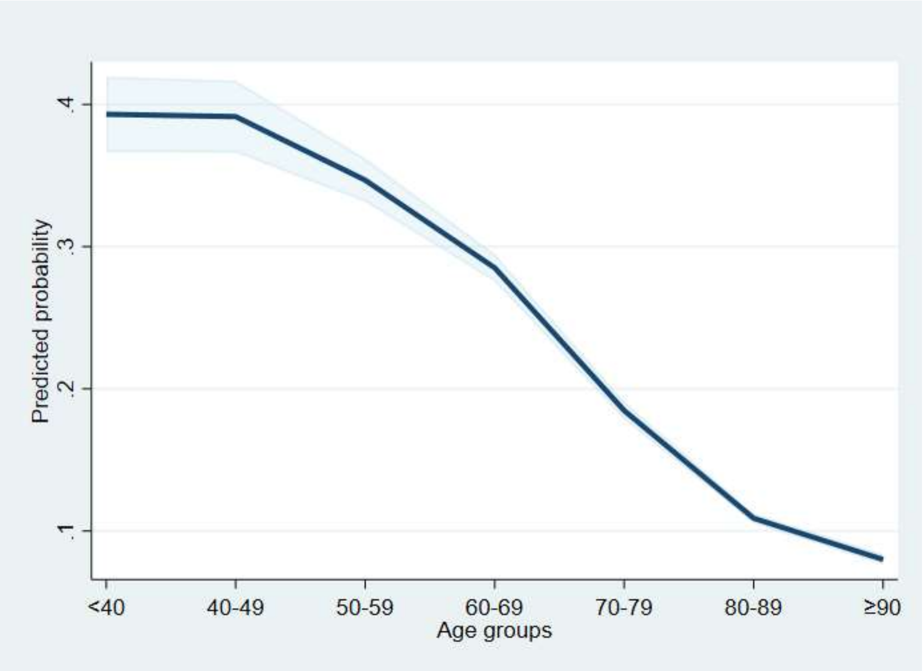


Figure 5. Predicted marginal probabilities of dying at home with respect to age
Multinomial logistic regression analysis: postestimation predictive margins with 95% CIs for dying at home with respects to age, keeping everything else constant.

Circulatory disease (34.9%) was the most common cause of death at home. The predicted probability of dying at home increased with 38.8% (CI 36.9, 41.6) when cause of death was symptoms/ill-defined and 8.9% (CI 6.9, 11.0) for external causes of death compared to circulatory disease. People dying from cancer had a 12.0% (CI -

12.6, -11.4) reduced probability of dying at home compared to circulatory disease. People living in municipalities with fewer inhabitants were more likely to die at home, with those living in municipalities with 2001-5000 inhabitants having the highest probability (17.8%, CI 17.0, 18.7). Receiving domiciliary care was associated with a 7.4% (CI 6.9, 7.9) increase in predicted probability, relative to not receiving domiciliary care. In the subpopulation of people who received municipal care, cohabiting reduced predicted probability of dying at home with 2.0% (CI -2.5, -1.5) relative to living alone.

We estimated that 5089 deaths, 41.9% of all home deaths and 6.3% of all deaths were potentially planned home deaths that occurred at home. Men had a higher proportion of both potentially planned (51.7%) and unplanned home deaths (61.5%). Men had a 5.9% (CI -4.1, -7.7) reduced predicted probability of a potentially planned home death in the adjusted analysis compared to women. In the population that received municipal care, women had 2.3% (CI -4.6, -0.1) reduced predicted probability of having a potentially planned home death, when also controlling for cohabitation. While 84.0% of cancer home deaths were potentially planned, this constituted only 10.2% of all cancer deaths. The proportion of potentially planned home deaths was 48.8% for circulatory disease, constituting 8.3% of all deaths from circulatory disease. Municipalities with <50,000 inhabitants were consistently associated with more potentially planned home deaths. The highest predicted probability was for municipalities with 5001-10,000 inhabitants (46.0%, CI 43.7, 48.4). For people who received domiciliary care, cohabiting increased predicted probability of having a potentially planned home death with 10.6% (CI 8.4, 12.9).

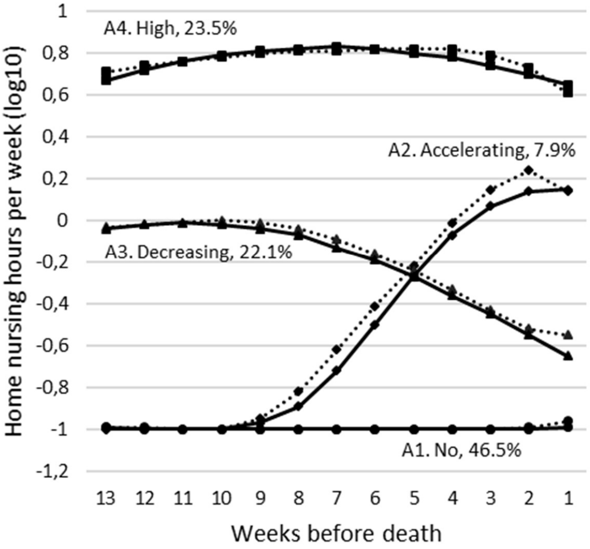
4.2 Paper 2

Out of 53,396 community-dwelling people, 22.2% died at home, 27.9% in a skilled nursing facility, 45.4% in a hospital and 4.5% in other locations. Men had a higher proportion of home deaths (58.0%). Cancer was the most common cause of death at home (22.1%) but constituted only 14.1% of all cancer deaths. Second most common was heart disease (20.7%), which constituted 28.9% of all deaths from heart disease.

We estimated four clinically interpretable trajectories of home nursing services simultaneously with four short-term skilled nursing facility trajectories for the last 13 weeks of life (Figure 6). Almost half the population followed a trajectory of no home nursing in the last three months of life. Nearly a quarter followed a trajectory with a high level of home nursing; almost 7 hrs/wk. This was the only home nursing service trajectory associated with dying at home compared to hospital (aRRR 1.29, CI 1.21, 1.38) in the fully adjusted model. This corresponds to a 3.5% (CI 2.4, 4.5) increase compared to people who followed the trajectory of no home nursing. A fifth of people followed a decreasing home nursing trajectory, which was associated with a reduced likelihood of dying at home (aRRR 0.90, CI 0.83, 0.97) compared to hospital. Approximately 8% followed a trajectory of accelerating home nursing. We found no significant difference between home deaths and hospital deaths (aRRR 0.93, CI 0.85, 1.03).

Almost 70% had a low probability of having a short-term skilled nursing facility stay at the end of life. Another 6.7% followed a trajectory of intermediate probability, 15.9% escalating probability and 8.4% increasing probability of a short-term skilled nursing facility stay. Trajectories of increasing (aRRR 0.40, CI 0.34, 0.47), escalating (aRRR 0.32, CI 0.28, 0.36) and intermediate skilled nursing facility (aRRR 0.65, CI 0.59, 0.72) were all associated with reduced likelihood of a home death compared to hospital, relative to the trajectory with low probability of a skilled nursing facility stay. People following the increasing and escalating trajectories had a very low predicted probability of dying at home of 4.6% (CI 4.0, 5.3) and 4.4% (CI 3.9, 4.9), respectively. Predicted probability of home death was 18.5% (CI 17.2, 19.9) for the intermediate trajectory and 28.5% (CI 28.1, 29.0) for the low trajectory.

A. Home nursing service



B. Short-term skilled nursing facility stay

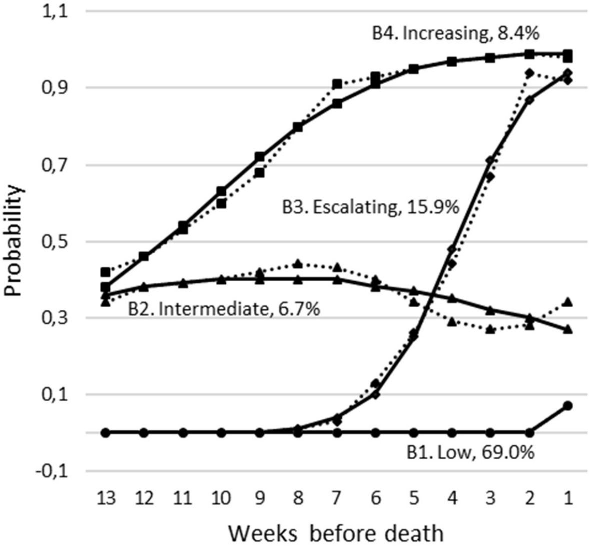


Figure 6. Home nursing service trajectories (A) jointly modelled with short-term skilled nursing facility trajectories (B) in the last 13 weeks of life.
Solid lines represent predicted trajectories, dashed lines indicate observed trajectories. Percentage of population for each trajectory are shown in parentheses. A) On the y-axis, 0 corresponds to 1 hrs/wk of home nursing and 1 corresponds to 10 hrs/wk.

In total, 24.0% of deaths were estimated to be potentially planned home deaths, regardless of actual place of death. Actual place of death for these 12,790 potentially planned home deaths was 27.1% at home, 18.0% in skilled nursing facilities, 53.8% in hospitals and 1.0% in other locations. In the entire deceased population within 2012-2013, this corresponded to 15.8% potentially planned home deaths, with 4.3% of all deaths being potentially planned home deaths occurring at home. Potentially planned home deaths were not associated with place of death in the fully adjusted model (aRRR 0.94, CI 0.89, 1.00).

Almost half (11.3%) the people with causes of death that predicted a potentially planned home death followed the high home nursing service trajectory. Nearly all people with potentially planned home deaths followed the trajectory with low probability of skilled nursing facility stays; regardless of which home nursing service trajectory they followed. People with unplanned home deaths followed trajectories with increased probability of skilled nursing facility stays to a larger extent.

4.3 Paper 3

Altogether, 14.3% of the population received ≥1 GP home visit, 42.7% ≥1 GP office consultations and 40.8% had GP interdisciplinary collaboration during the last 13 weeks of life. Likewise, 12.0 received ≥1 OOH home visit and 20.0% had ≥1 OOH clinic consultation. People were hospitalized a median of four days (25th-75th percentile 0-14). Figure 7 shows how these contacts developed over the last 13 weeks of life.

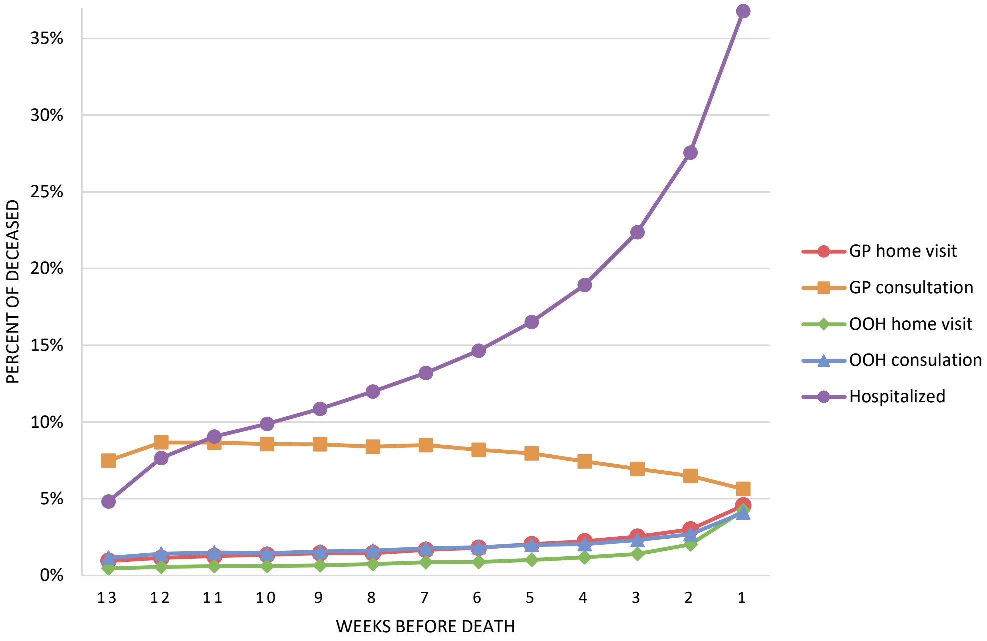


Figure 7. Contacts in the last 13 weeks of life.
Percentage of all deceased with ≥1 of contact types: general practitioner (GP) home visit, GP office consultation, out-of-hours (OOH) home visit, OOH consultations and/or hospitalization each week in the last 13 weeks of life.

During the last four weeks of life, 7442 people (9.2%) received ≥1 GP home visit (range 1-28), of which nearly a third (2.6%) died at home. Likewise, 6.6% of patients received ‘appropriate follow-up’ with ≥1 home visit when the GP had ≥1 interdisciplinary collaboration. Table 5 shows adjusted OR for dying at home when receiving various health care services during the last 13 weeks of life. GP home visits and GP interdisciplinary collaboration were positively associated with dying at home compared to any other location in a dose-dependent relationship.

Table 5. OR for dying at home compared to any other location of death (nursing home, hospital, other) and associations with contacts with GPs, OOH services and days spent in hospital during the last 13 weeks of life.

	Adjusted OR	**(CI)**	**p**	**Predicted probability (%)**	**(CI)**
GP home visit (ref. 0)					
1	1.92	1.71, 2.15	<0.001	3.3	2.7, 3.9
≥2	3.49	3.08, 3.96	<0.001	6.5	5.8, 7.2
GP office consultation (ref. 0)					
1	0.87	0.80, 0.94	0.001	-0.7	-1.1, -0.3
≥2	0.80	0.74, 0.86	<0.001	-1.1	-1.5, -0.8
GP interdisciplinary collaboration (ref. 0)					
1	1.76	1.59, 1.96	<0.001	2.8	2.3, 3.3
≥2	2.52	2.32, 2.74	<0.001	4.6	4.2, 5.0
Out-of-hours home visits (ref. 0)					
1	1.04	0.92, 1.17	0.553	0.2	-0.4, 0.8
≥2	1.26	1.03, 1.54	0.024	0.1	0.1, 2.2
Out-of-hours consultations (ref. 0)					
1	0.85	0.77, 0.92	<0.001	-0.8	-1.3, -0.4
≥2	0.78	0.67, 0.90	0.001	-1.3	-2.0, -0.5
Hospital days	0.95	0.94, 0.95	<0.001	-0.3	-0.3, -0.3

OR: Odds ratio. GP: General practitioner. OOH: Out-of-hours. Predicted probabilities represent change relative to reference category.

The number of GP home visits (1: IRR 1.21, CI 1.16, 1.26 and ≥2: IRR 1.39, CI 1.33, 1.46), GP office consultations (1: IRR 1.38, CI 1.34, 1.44 and ≥2: IRR 1.63, CI 1.58, 1.68) and GP interdisciplinary collaborations (1: IRR 1.51, CI 1.45, 1.57 and ≥2: IRR 1.94, CI 1.88, 2.00) were associated with patients having an OOH contact in a dose-dependent manner. Having ≥1 GP office consultation or GP interdisciplinary collaboration resulted in nearly three more days hospitalized. While one GP home visit increased IRR of hospitalization resulting in a one-day increase in days hospitalized, there was no difference between people who received zero or ≥2 home visits.

5. Discussion

5.1 Methodological considerations

5.1.1 The material

Research in palliative end of life care has potential ethical challenges related to carrying out primary data collection in clinical studies, due to patient and caregiver burden, vulnerability of participants, consent and capacity issues.[137] Routinely collected data can be used to follow patients over time, including utilization of health care services, without potentially adding burden.

This thesis aims to investigate the relationship between health care services, sociodemographic factors and dying at home. All three papers used routinely collected data. Data was registered prospectively by the registries and collected retrospectively by the researchers. **Paper 1** had a cross-sectional design, whereas **Paper 2** and **3** were longitudinal. Data was linked with information from several official registries and databases, covering the entire Norwegian population. The Regional Ethical Committee granted exemption from confidentiality, and data were collected without consent from participants. Steps were taken to ensure confidentiality of study participants, of which the most important in this thesis were: 1) No actual dates were used. Date of death was set to day zero and all events decremented for each day of the last 90 days of life. 2) Age was grouped into intervals of 5-10 years. 3) In **Paper 1** and **2**, cause of death had a lower detail level for younger age groups. Data used in **Paper 1** and **2** were anonymous. In **Paper 3**, they were indirectly identifiable. Information about the quality of the linked registries and databases are discussed in Section 3.1.

An evident strength of using routinely collected data, is that we could include a large study sample, covering the entire population of individuals who died over two whole years. This has the potential to provide robust population-level measures of the utilization of health care services and quality of end of life care; shed light on patterns of use of health care services; and be helpful for developing a public health approach.[138, 139] We believe we are the first to thoroughly quantify health care service utilization at the end of life at a population level in Norway.

Palliative end of life research has issues related to selection and recruitment of participants.[137] Selection bias occurs when there are systematic differences between subjects included in a study and those who are not included; and further bias can be introduced through systematic differences in non-response or attrition by participants in a study.[137] We largely avoid problems of selection bias, non-response bias and attrition bias. Norway's universal healthcare ensures more equitable access to health care services, although differences in access or use of services is a problem. By using registry data, which in Norway contains individual-level socioeconomic data, we are able to include hard to reach populations, such as individuals who are not identified as being in need of palliative care, nearing the end of life, or never receive health care services at the end of life.[139] Recall bias, a systematic error which occurs because of inaccurate or varied recall from study participants,[137] is largely avoided when using registry data. Missing values are also a minor problem (see Section 3.3).

Several limitations apply when using registry data in research. Routinely collected data is registered prospectively on an individual level, but not necessarily or only for research purposes.[139] Analyses are limited by what type of information is available. We chose measures previously related to dying at home that was available in the registries used in the thesis, but other factors may influence the ability to remain at home that we did not have access to. In all three papers, we could not account for specialized palliative care. The exception was hospital admissions where the main reason for admission was palliative care, which in our material was negligible (128 hospital admissions with ICD-10 diagnosis Z515, 91% cancer-related).

We could not investigate the quality or appropriateness of health care services provided. Patient reported outcomes, including preferences regarding end of life care or quality of life, the quality of family relationships, support or caregiver burden are unavailable. Instead, we used indicators of whether appropriate care was provided or not. Quality indicators for appropriate and inappropriate health care services at the end of life has been developed when using population-based administrative data across health care settings, to assess the performance of a health care system relating to end of life care.[140] Acceptability and validity have been assessed through expert meetings and feasibility tested with administrative data.[140, 141] Across conditions, quality indicators in end of life care include timely receipt of palliative care, hospital admissions, emergency department admissions, home death versus hospital death, and GP contacts.[140]

Another important limitation when using registry data is related to access and linking of data. Due to regulations requiring all data involving the IPLOS registry to be anonymous, we could not link all the information that we initially planned. Lacking information about home nursing services and skilled nursing facility care would be a great loss to our study, and a pragmatic solution was to divide it into two substudies. This led to substudy 1 linking data from IPLOS and NCoDR (**Paper 1** and **Paper 2**) and, substudy 2 linking data from NCoDR, KUHR, NPR, Statistics Norway and the Norwegian Prescription Database (**Paper 3**). The Norwegian Prescription Database linked the data for substudy 2, but no prescription data were used in **Paper 3**.

A consequence of this division is that we could not make direct inferences about the relationship between nursing services (home nursing and skilled nursing facilities) and physician led services (GP, OOH, hospital) in relation to the end of life or dying at home. In **Paper 3** we partly accounted for home nursing services by investigating GPs' interdisciplinary collaboration, which is predominantly with home nursing services. Additionally, we accounted for people with long-term skilled nursing facility care in regression models in **Paper 3**, with a prediction model for the probability of long-term skilled nursing facility care based on data from substudy 1 (IPLOS and NCoDR).

Accessing data was time consuming. We started the application process in December 2014 with an application to the Regional Ethical Committee, followed by applications to the Data Protection Authority and the individual registries and databases. One year later, in December 2015, IPLOS declined our application. Another nine months went by before issues related to data linkage with IPLOS were resolved. Data for substudy 1 was delivered in March 2017 and data for substudy 2 was delivered in June 2018. It took 3.5 years from the application process started until all data were received by the researchers. Problems with accessing data have also been reported by other researchers as cumbersome, time consuming and costly; in which we agree.[142, 143] It is also inefficient use of resources and may lead to delay of important research findings.[142]

5.1.2 The measures

Potentially planned home deaths

Most research on planned home deaths are clinical interventions to try to enable more home deaths, studies about congruence between preferred and actual place of death or the presence of specialized home palliative care in a population.[34, 39, 52, 144-147] These studies do not give information about the proportion of dying people who plan to stay at home at the end of life. We did not have information about patient or caregiver preferences regarding place of care at the end of life or place of death or whether plans were made to stay longer at home or die at home. Instead, we used an indirect method to estimate the number of potentially planned home deaths. The goal was not to estimate peoples' preferences, but rather differentiate between people whose deaths appeared sudden or unplanned from those where health care service utilization implied that resources were allocated to facilitate time at home and possibly a home death.

While *estimate 1* (Figure 3, p 34) was based on receiving domiciliary care anytime during the last three months, we chose receiving home nursing services within seven days before death as the latest time compatible with receiving palliative care at home in *estimate 2* (Figure 4, p 35). We evaluated how sensitive the estimate was to changes in timing of home nursing by replacing seven day with 14 days before death. The change resulted in 813 more deaths being classified as potentially planned home deaths (1.5% absolute increase). For most people, receipt of home nursing services started at an earlier time.

The decedents with diagnoses most likely to receive palliative care were used in the estimates, and probably led to misclassification of some individuals. Cause of death criteria were more inclusive in *estimate 1* than in *estimate 2*. Especially in *estimate 1*, deaths from acute illness may have been classified as potentially planned to occur at home. We thus adjusted *estimate 2* in **Paper 2**, to correct for this likely misclassification. The two estimates show that potentially planned home deaths that occurred at home were rather similar, with 6.3% of all deaths in *estimate 1,* and 4.3% in *estimate 2.* Still, people dying from other conditions than those included in our definition may have had planned home deaths.

We do not know of anyone else who has estimated number of deaths potentially planned to occur at home, which makes comparison with other research difficult. In a Canadian study with 1306 informants, 46% of decedents had voiced a preference about place of death to their next-of-kin. While 75% preferred to die at home, nearly 40% actually died at home.[146] Similarly, in an English study with 1422 informants, 36% of family caregivers had knowledge about the deceased person's preference about place of death. Of these, 74% expressed a preference to die at home, while only 13% died at home.[148] Both these studies show incongruence between preferred and actual place of death, but may not be generalizable due to small study populations and design with questionnaires/interviews with bereaved relatives. The substantial difference is somewhat similar to the difference we found when estimating potentially planned home deaths for community-dwelling people and actual home deaths. The results are not directly comparable, but may give an indication of how our estimates perform.

Although our data cannot give information about preferences or plans to stay at home at the end of life, we believe our estimates of potentially planned home deaths represent a valid indication. Without the support of home nursing services, planned home deaths would not be feasible for most people and the presence of this services itself signals facilitation of staying longer at home. Our finding that people with potentially planned home deaths for the most part had a low probability of having short-term skilled nursing facility stays and that 47% followed the trajectory with a high level of home nursing services, indicates that time at home and possibly a home death was prioritized. However, we cannot exclude that some people died at home with help primarily from family caregivers and/or specialized palliative care services.

People dying from cancer have a higher probability of receiving specialized palliative care.[48, 49] Additionally, people with potentially planned home deaths are unlikely to have an unknown or sudden underlying cause of death, which we accounted for in our estimates. Since palliative care is mostly provided to cancer patients, we believe our more inclusive estimates represent an overestimation rather than an underestimation.

Health care services

For all measures of health care services, we can account for the presence of a specific service from valid sources, but not the specific content or quality of the service.

Information about home nursing services and skilled nursing facility stays from IPLOS is based on municipalities' report of service decisions including type of service and assigned amount of time each week, but not the actual service provided. These decisions are based on assessed needs of the recipient and may be interpreted as a proxy for the person's function at the end of life. Although assessments may be more valid for activities of daily living than cognitive impairment (see Section 3.1.2), we believe this is not critical when assessing home nursing services at the end of life, since most people with dementia reside in skilled nursing facilities at the end of life in Norway.

Information about GP and OOH contacts is based on billing claims covering >99% of all billing claims. It is considered a reliable information source regarding contacts between patients and physicians. We excluded 42 billing claims with errors, out of >480,000 billing claims in our data material; too few to have influenced our results. The Norwegian Health Economics Administration has strict control of claims and variation in fee codes, which leads us to assume high consistency in use of fee codes among physicians, including the fee for contact type. It is a strength of our material that we could connect patients with their personal GP and thus account for variations explained by differences between GPs regarding e.g. home visits to patients.

It is a major limitation that we could not directly look at interactions between nursing services and physician services in primary care, since we were not given permission to link these data. We used the fee codes for communication with other municipal professionals regarding the patient (n=32,267) and interdisciplinary meetings (n=697) to measure the GPs interdisciplinary collaboration. Although some of these contacts probably were with other professionals such as physiotherapists, a majority were with home nursing services. Thus, we used this measure as a proxy for interdisciplinary collaboration between GPs and home nursing service.

Cause of death

Cause of death is a common measure to classify people in palliative end of life research using administrative data. Cause of death in NCoDR refers to the underlying cause of death, meaning the illness or injury that started the path leading to death, and not necessarily the immediate cause of death. Around 50% of underlying causes of death are identified automatically, while 50% require manual assessment and sometimes additional reporting.[113] It is a problem that few causes of death are verified by autopsy. However, differences in cause of death determined from death certificate and autopsy in autopsy studies are challenging to interpret, due to the highly selected population autopsies are performed on. The results are probably not directly transferable.[113] Use of unspecific codes have lowered the score of NCoDR in quality assessments, but is generally assessed as high. Death certificates are similar and comparable across countries, making cross-national comparisons more reliable.[113] In **Paper 1** and **Paper 2**, the age group 0-39 years had a lower detail level for cause of death than older age groups. We do not think it has substantially altered our findings since we mainly used main chapters in the European Shortlist for Causes of Death.

Family caregivers

We did not have any information about whether the decedents had family caregivers or the extent of such care. We used household in **Paper 1** and **2**, and marital status and number of children in **Paper 3**, as proxy measures for the presence of a family caregiver. There is a risk of misclassification, because the presence of a family member does not give any information about their involvement in end of life care. Children may not be living close by, be estranged, not be able or wish to provide care at the end of life. A spouse or partner may be a stronger indicator, since elderly people are more likely to receive care by their spouse or partner than their children.[111]

However, the spouse or partner may be unable to provide care due to various circumstances, such as his/her own functional impairment or by living in a skilled nursing facility. Additional risk of misclassification applies to the household variable used in **Paper 1** and **2**, due to 1) IPLOS' definition of cohabitation (see Section 3.3: Covariates); and 2) this variable was only available for the population registered in IPLOS. Because of this, results regarding family caregivers should be interpreted with caution.

5.1.3 Statistical methods

We chose to include Pearson Chi Square tests with p-values for bivariate analyses in **Paper 1** and **2**. However, since we included the whole population of deceased, observed differences represent actual differences. In line with this, only proportions were presented in **Paper 3**.

From regression analyses we show both confidence intervals and p-values to indicate the direction of the association and the statistical significance. Some of our measures were estimates or proxy measures, which means associations should be interpreted with some caution. The large study population yields high precision, which is reflected by narrow confidence intervals, and makes it more important to evaluate whether results represent meaningful differences. The observational design in this thesis means that our findings are associations and cannot be interpreted as causal relationships.

The cross-sectional design in **Paper 1** is useful for investigating associations between individual factors and associations with dying at home but is not useful for investigating the development of health care services provided.

In **Paper 2** we investigated the development of home nursing services and short-term skilled nursing facility stays with a group-based trajectory model. This method identifies groups of individuals who follow a similar developmental trajectory of the outcome of interest with a maximum likelihood method, in our case, nursing services.[149] One major advantage of this method, is that we do not have to make any prior assumption about groups, which makes it possible to identify trajectories we did not anticipate. Each group is conceptually thought of as a collection of individuals following approximately the same developmental trajectory,[149] and not based on variation around a population mean or application of hierarchies. Furthermore, the statistical approach to identifying groups can separate random variation from real differences within the population.[149] The method also gives probabilities of group membership for each individual as a measure of uncertainty. Factors associated with specific group membership are considered after model estimation. Model selection is based on statistical tests and objective standards, but also clinical judgement about the models, which may be considered a limitation. It is a reminder that group-based trajectory models represent an approximation of reality.[149]

Results in **Paper 3** give the impression of a lower proportion of persons receiving GP services than the actual proportion. The population at risk of receiving such services is lower than the total population, since people in long-term skilled nursing facility care are not at risk of receiving GP services (see Section 3.4 Statistical analysis: **Paper 3**). OOH services and hospitals are correctly presented, since these services provide care also to long-term skilled nursing facility residents.

We could not identify people who were in long-term skilled nursing facility care in **Paper 3**. To reduce bias in analyses, we used propensity score covariate adjustments for the probability of being in long-term skilled nursing facility care. Propensity score covariate adjustment means that the propensity score was used as a predictor to reduce confounding in the multivariable logistic regression model with place of death as outcome.[150] Propensity scores are limited by the quality of the propensity score model. In our model, we had a large study sample and the model fit was excellent (see Section 3.4 Statistical methods: **Paper 3**). By using propensity score covariate adjustment, we reduced bias in our estimates of health care service associations. In retrospect, we realize we should have asked for data in this substudy to include community-dwelling people only.

5.2 Discussion of study results

Few people die at home in Norway. The proportion of home deaths is somewhat modified with 22% deaths occurring at home when considering only the community-dwelling population. Although we estimated that almost a quarter of community-dwelling people may have had potentially planned home deaths, only a minority occurred at home. In the following sections I will discuss some of the factors related to dying at home in Norway, with a focus on individual factors and health care services in relation to dying at home.

5.2.1 Individual factors

Sex and age

Studies from other countries are varying in the relationship between home death, sex and age.[7, 15, 35, 38, 151] Although more women died in our study, a larger proportion of men died at home. In adjusted analysis the results regarding sex were conflicting. Predicted probabilities were small, with men having a 2.1-2.4% higher predicted probability of dying at home in **Paper 1** and **2**, but 3.6% lower in **Paper 3**. For deaths outside the home, women died more often in skilled nursing facilities and men more often in hospitals, similar to findings in a Swedish study.[8] The difference between the sexes may be linked to that women traditionally provide care to a spouse at home and that women die at an older age. Variations we found related to sex are small in adjusted analyses, and is probably in itself not a key factor for staying at home at the end of life.

Absolute number of home deaths were higher for the older age groups, but a higher proportion died at home within younger age groups. Altogether, 26.5% of people <70 years died at home, but only 11.8% ≥70 years. In adjusted analysis there was a clear age trend where younger age was associated with dying at home in both the total population and among community-dwelling people. Among the community-dwelling, people aged 40-49 years had the highest odds of dying at home compared to hospital. In **Paper 1**, potentially planned home deaths were associated with increasing age but decreased from 70 years in a subgroup controlling for cohabitation. A Norwegian study found that changes in place of death with less hospital and home deaths and accordingly more skilled nursing facility deaths, could largely be explained by changes in the population of decedents, with people dying at an older age, women living longer than men, and a shift to more people dying from chronic debilitating conditions.[4] Place of death may also be influenced by differences in access to and quality of health care services at the end of life for different age groups. Adsersen et al. found that older Danish cancer patients were less likely to be admitted to specialized palliative care,[152] while Lindskog et al. found that older age was associated with a risk of poor end of life care quality for Swedish cancer patients.[153] Another study compared palliative care in Spain, Italy and Belgium, and found that the quality of general palliative care could be improved for older age groups.[154]

Cause of death

Circulatory disease and cancer are the most frequent causes of death in Norway and were also most frequent causes of death at home in this thesis. Several studies have compared end of life and palliative care for cancer patients and other patient groups. The findings are highly consistent across all studies, in pointing out the inequalities between cancer patients and other patient groups in both recognition of needs, and access to appropriate care at the end of life.[52, 53, 56, 76, 155-157]

We found that people with cancer had lower relative risk ratio of dying at home in adjusted analyses compared to circulatory disease. Only 12% died at home and >70% died outside their permanent residence (38% hospital, 35% short-term skilled nursing facility). Despite this, a larger proportion of people dying from cancer (within diagnosis group) had potentially planned home deaths, both regardless of actual location of death and which occurred at home. Almost 60% of people dying from cancer received home nursing services, and they constituted the largest diagnosis group in all the trajectories receiving home nursing services. A larger proportion of cancer patients received GP home visits and had the GP involved in interdisciplinary collaboration. They also had less OOH contacts, but the most hospitalizations.

Our findings support previous findings that people dying from cancer receive more ‘appropriate’ health care services at the end of life. At the same time, they spend more time hospitalized and rarely die at home. This phenomenon of more ‘appropriate’ end of life care not necessarily leading to doing less of other things or more time spent at home, has been showed previously.[158]

Dementia is in the top-five list of causes of death in Norway.[159] Only 0.3% of all deaths were caused by dementia and occurred at home, while almost 1% had dementia mentioned on the death certificate and died at home. As expected, the vast majority died in long-term skilled nursing facilities. Although approximately 80% of people in long-term skilled nursing facilities have dementia,[160] only 17% of long-term skilled nursing facility deaths in our material were categorized as caused by dementia, while 32% had dementia mentioned on the death certificate. This suggests that dementia is under-reported as cause or contributing cause of death. Our findings may also reflect that dementia is a progressive disease with early, prolonged and severe functional decline,[59, 161] which makes it harder to stay at home towards the end of life, and may not be feasible for the majority of persons living with dementia. A recent Belgian study found that community-dwelling people with dementia received less palliative care than cancer patients, and changes over time in use and timing of palliative care were lower among this group than other groups dying of conditions indicative of palliative care.[162] One reason may be perceived difficulty in recognizing the end of life, but also in acknowledging dementia as a terminal illness.

Another important finding is that it appears people are more likely to die unplanned at home from conditions that are more often a result of acute illness, such as an acute cardiovascular event, ill-defined or external causes. In adjusted analyses in **Paper 1**, people with ill-defined or external causes of death had a higher relative risk ratio of dying at home. Furthermore, people who died at home were more often men, lived alone or were without a family (partner and/or children). All registered deaths at home from ill-defined or external causes were men in our material, and men also died more often at home from circulatory disease. These findings are not surprising with a very low number of total home deaths. Findings from other studies support our findings, and suggest that a large proportion of sudden unexpected deaths (a majority cardiac deaths) occur at home, more often among men, and a majority among older patients.[163-165]

Overall, cancer patients appear to receive the most ‘appropriate’ end of life care in primary health care, as well as specialized palliative care, but are unlikely to die at home. Frail people dying from dementia are especially disadvantaged in staying at home and mostly die in long-term skilled nursing facility care. A large proportion of home deaths appear to be sudden unexpected deaths. Our findings warrant more focus on clarifying the goals of the patient and caregivers at the end of life. There are many missed opportunities to identify and provide palliative care to enable people to stay longer at home; especially among non-cancer patients.

Family caregivers

Previous studies have shown that having a family caregiver is very important to be able to die at home.[34] In Norway, elderly people receive more help from their spouse than their children.[111] Those who have a spouse or child receive less municipal health care services, especially when the spouse or child is female, and imply that family caregivers substitute official health care services.[166] While family caregivers are important for staying at home at the end of life, and provide a substantial amount of care,[111] changing family structures may be contributing to declining home death rates. Norway has a high employment rate, also for women,[167] who traditionally provide such care. Divorce and breakups are common,[168] and birth rates are declining.[169] All these factors may contribute to lower availability of care provided by the family.

Our results about family caregivers should be interpreted with caution due to limitations discussed in Section 5.1.2 and small differences between groups. We found that dying at home was associated with living alone, being unmarried and without children. Potentially planned home deaths were associated with living with someone. These findings fit well with a high proportion of sudden and unexpected deaths occurring at home. Family caregiver burden may be high.[170-173] Uncertainty about what to expect due to lack of planning and inadequate support from the health care system,[171] in addition to limited time to provide care, may result in having their loved one moved to an institution feeling safer than staying at home. This may partly explain our finding with increasing probability of being admitted to a short-term skilled nursing facility towards the end of life, and that over a third of the population was hospitalized in the last week of life.

A Norwegian qualitative study found that older community-dwelling cancer patients and their family experienced that health care services were not tailored to their needs in the palliative phase,[174] and may clarify why many do not remain at home at the end of life. They experienced exhausting cancer follow-up in hospitals, where especially travels between the home and hospital led to patients discontinuing follow-up. Many frail patients had trouble visiting their GP's office since many GPs did not offer home visits, and some had low confidence in the GPs competency. Additionally, the patient's family felt they were not involved, received little information and experienced that care was fragmented with little continuity of care from hospital, home nurses, and the GPs.[174] Continuity of care is important to ensure that the patients and families feel safe at home.[175]

5.2.2 Health care services

Home nursing services

A quarter of the community-dwelling population received a high amount of home nursing services, almost 7 hrs/wk, of which half had potentially planned home deaths. Only the high home nursing trajectory was associated with dying at home in adjusted analyses. Our results complement findings that specialized palliative home nursing or multidisciplinary teams increase the likelihood of dying at home,[34, 39, 176, 177] by showing that also regular home nursing of a certain intensity and continuity was associated with an increase the likelihood of dying at home. The absolute increase in predicted probability for dying at home was small (3.5%) compared to receiving no home nursing services. Still, continuity of care may have contributed to some patients and their families feeling safe at home,[41] and have given home nurses confidence in assessing and treating distressing symptoms because they knew the patient and family.

Webber et al. showed that implementation of a home-death planning tool (advance care planning) and a home medication kit in publicly funded home nursing services increased the likelihood of dying in the community.[178] There were also indications of a reduction in hospitalization in the last six month before death.[178] Norwegian home nurses also reported that use of a medication kit and planning together with the patients GP increased confidence in providing end of life care at home.[179] Another recent qualitative study from Norway found that both home nurses and GPs experienced in providing palliative care, underlined collaboration between the patient, family, primary and secondary health care for palliative care at home to be effective.[180] Especially, a good start and safe discharge routines from hospital were emphasized.[180]

Receiving <1 hour per day of home nursing at the end of life is little when we know that most dying people have substantial functional decline towards the end of life.[59, 60, 62, 161] It is thus not surprising that e.g. the accelerating home nursing trajectory, starting closer to death and amounting to <2 hrs/wk of home nursing was insufficient to stay at home, even if more time at home may have been a priority. People following this trajectory were more likely to die in a short-term skilled nursing facility.

Almost 9% of the community-dwelling population had decreasing home nursing and a low probability of being admitted to short-term skilled nursing facility care. This could represent a situation where family caregivers took responsibility for end of life care at home. Other likely scenarios are that death was sudden, unexpected or that they were followed by secondary health care services. Nearly 60% in this group died in a hospital, and 80% had a cause of death indicative of palliative care needs.[6]

We found that just over half of community-dwelling people received home nursing services at the end of life and 70% had a low probability of being admitted to short-term skilled nursing facility care. More than half of those who receive home nursing are living alone,[24] and it may not be feasible to stay at home at the end of life even if professional support is provided. For some, a transition to a skilled nursing facility or hospital may be appropriate due to lack of symptom control, or high caregiver burden or absence of a family caregiver. Although we do not know the preferences of the decedents, our findings point to a need for more advance care planning and that more people could benefit from receiving general palliative care from home nursing services. For this to be successful, increased knowledge, skills and experience in caring for dying patients, along with time, available equipment and tools is needed.

General practitioners

Previous studies have shown that GPs are important in providing general palliative care at home by offering continuity of care, by performing home visits and collaborating with other health care professionals, especially for cancer patients.[73, 81, 85, 86, 140] A study in four European countries found that GPs were aware of their patients' preferences regarding place of death in <50% of cases when the patient died non-suddenly from cancer; a majority preferred to die at home. Those who had a known preference and received palliative care from their GP had greater chance of dying at home.[31] Our findings confirm that follow-up from GPs at the end of life in form of home visits and interdisciplinary collaboration is associated with more home deaths. Both factors increased the probability of dying at home in a dose-dependent manner, but the absolute effects were small for each component (Table 5, p 49).

Together with the high home nursing trajectory, GP home visits and interdisciplinary collaboration constituted the three types of health care services positively associated with dying at home in Norway. Almost a quarter of community-dwelling people received such home nursing services (the population at risk). In total, 12% of the population received home visit(s) and interdisciplinary collaboration in combination in the final three months of life. This corresponds to 18% of the community-dwelling population. Only 7% of patients received both home visit(s) and had a GP collaborating with other healthcare professionals in the last four weeks of life, corresponding to 10% of the community-dwelling population. A Norwegian report found that many patients are satisfied with their GP, but few patients who reported a need for GP home visits received it.[181] One reason for not providing palliative end of life care is probably lack of timely recognition of palliative care needs or not anticipating that the end of life is close, and not going through the process of advance care planning.[67-69, 182-185]

In 2012 the Coordination reform was implemented in Norway with a goal to improve coordination and collaboration between primary and secondary healthcare due to fragmented health care services and increasing costs.[20] Responsibilities and tasks were transferred from secondary to primary health care to achieve a goal of patients getting health care services closer to home, reduce hospitalizations, relieve pressure on secondary health care services and lead to cost reductions.[20] As a consequence municipalities and GPs are now responsible for taking care of more patients with chronic illness, but also older, frail and multimorbid patients.[186] The reform has been successful in reducing hospitalization length, but has also led to more rehospitalizations.[187] It is unknown if patient pathways have improved and become more cohesive.[187]

In a recent Norwegian qualitative study investigating GPs' collaboration with municipal health care providers, GPs presented prioritization due to limited time as a main reason for lack of collaboration, while collaboration partners described large individual differences in GPs' willingness to collaborate.[188] Organizational differences between GPs and collaboration partners and bureaucratic routines was reported to hamper collaboration. There were also examples of GPs being left out in collaboration between primary and secondary health care services.[188] Excluding GPs in collaboration across health care levels and variable collaboration within primary health care has been reported by others as well, and may reduce patient safety.[180, 189] Many patients, their families and health care professionals regard GPs as central in providing palliative care.[75] There is a need for increased competency, better interprofessional collaboration and coordination through a better framework in provision of palliative care to community-dwelling patients.[75] However, evidence from a systematic review suggests that strategies for enhancing collaborative working in palliative care is often a result of informal interactions rather than systematic processes.[190]

Recommendations that primary health care physician full time equivalents should be increased by 50% to meet requirements that came with the Coordination reform has not been followed up.[186] GPs have been little involved in development of agreements between primary and secondary health care that became mandatory with the reform, but has experienced a significant increase in workload; especially work without direct patient contact.[186, 187, 191] This may explain an ongoing recruitment and retainment crisis in in Norwegian general practice today.[192] It may be challenging to add to the workload of GPs with a demand of more involvement in palliative end of life care without addressing responsibilities and organizational factors first.

Out-of-hours services and hospital

We found that GP office consultations were associated with reduced probability of dying at home, but the absolute effect was small (1 consultation: -0.7%, ≥2 consultations -1.1%). It goes well together with other health care services that bring the patient out of their own home: OOH office consultations, hospitalizations and skilled nursing facility stays, which all reduced the probability of dying at home. Furthermore, both GP consultations and GP interdisciplinary collaboration was associated with a three day increase in days hospitalized and increased the probability of having an OOH contact at the end of life. Most decedents, however, did not have any OOH contacts. Hospitalizations on the other hand, escalated towards the end of life, especially in the last week before death with more than a third of all admitted to a hospital. Interestingly, while one GP home visit was associated with one more day hospitalized, ≥2 GP home visits was not associated with more hospitalization; and could be an example of better resource use on a population level.[193] We do not know how many of the hospitalizations were appropriate, but hospitalization at the end of life is considered an indicator of inappropriate end of life care.[140]

Our findings are similar to results from other European countries, which have also found that when the GP had knowledge of the patient's preferred place of death, the probability of being hospitalized was lower.[194] However, an increased or large number of GP contacts in the last weeks of life has been associated with a reduced likelihood of dying at home and higher likelihood of hospitalization and hospital death.[31, 83] One interpretation is that greater symptom burden and needs required a higher level of health care services. Another explanation may be that primary health care services are mainly reactive rather than proactive due to a lack of planning and anticipation of needs.

In a Danish study, GPs reported they often or always offered end of life care to 85% of cancer patients and 34-40% of patients with non-malignant disease.[94] An Australian study found that up to a quarter of GPs did not involve themselves in palliative care at all.[87] Altogether, around 60-80% of deaths are non-sudden, as judged by physicians retrospectively after death.[195-198] These findings point to that more deaths could have been anticipated and the patient been offered advance care planning and general palliative care, initiated by a more proactive GP. Reasons for not delivering palliative care include lack of knowledge, skills or confidence in providing palliative care (both symptoms and psychosocial aspects), not recognizing palliative care needs of patients, bureaucratic procedures, difficult communication between healthcare professionals, lack of continuity and collaboration between services, continuity OOH, limited resources and time, having other commitments, and sometimes lack of interest.[87, 88, 199]

End of life care may be organized to reduce hospitalizations at the end of life by improving communication about care preferences and having a more involved GP who has knowledge about end of life care.[194] Previous studies have found that the GP is involved in only 25-46% of hospitalizations of their patients, with patients and/or families, OOH services, outpatient clinics or agreements directly with hospital wards being responsible for the rest.[32, 200, 201] This may be due to other health care services not involving the GP in decisions about hospitalization, but also lack of involvement or unavailability of the GP.

6. Conclusions

This thesis has investigated home deaths in Norway in relation to health care service utilization at the end of life and differences in personal characteristics of decedents.

We found that few people died at home in 2012-2013. A majority of deaths appears to have been unplanned to occur at home, including home deaths.

The most common causes of death at home were circulatory disease and cancer. More men than women died at home. Dying at home was associated with persons who were younger, unmarried/living alone, and without children. People dying at home had a higher probability of living in municipalities with fewer inhabitants from causes death more likely to be sudden and unexpected (external, ill-defined or circulatory disease). A larger proportion of persons dying from cancer were estimated to have potentially planned home deaths than those dying from other conditions.

Dying at home was associated with receiving a high number of home nursing hours per week in the last three months of life, receiving home visits from GPs and interdisciplinary collaboration. Few people received such services, indicating that few received appropriate primary health care services at home at the end of life. Health care services that required the patient to leave their own home, such as GP office consultations, short-term skilled nursing facility stays, OOH office consultations and hospitalizations reduced the likelihood of dying at home.

GP contacts increased the probability of patients having an OOH contact, but few people had OOH contacts. Hospitalizations escalated towards the end of life. All GP contacts except ≥2 GP home visits were associated with more days hospitalized.

Our results indicate inequities at the end of life when investigating both individual factors and use of health care services. GPs and home nurses may enable more time at home or home deaths for people who have this preference. The potential for delivering palliative end of life care at home is not utilized in primary health care today.

7. Implications and future perspectives

At a population level, follow-up from GPs and home nursing services at the end of life may enable people to die at home. Our results imply that most people dying in Norway do not receive enough appropriate follow-up to make a home death feasible. Primary health care is under strain. With increasing workload, limited resources and time it may not be surprising that home deaths continue to decline. According to official palliative end of life care guidelines, care that enables people to die in their preferred location should be faciliteted.[202] Although we do not know how many people prefer to die at home in Norway, it is likely that many people do not have their preferences met.

Specialized palliative care is a crucial part of our health care system, but it is unlikely that they will be able to provide care to all people with life-threatening illness and palliative care needs. Specialized palliative care should be delivered to those with complex needs and offer support to general palliative care providers. With the right resources, general palliative care can be offered by GPs and home nursing services to more patients who are approaching the end of life.[193] They are in a good position to do so. Many people have a long-standing relationship with their GP, and some receive home nursing for an extended period. This continuity may be of great value when patients approach the end of life. It may also be possible to provide palliative care to most patients who are in need, regardless of diagnosis, age, sex or socioeconomic status. The potential for palliative end of life care at home from primary health care is currently not utilized.

Death is an inevitable part of life. The question is whether we should accept that dying is institutionalized. If not, a good place to start would be to start talking about death and dying and about our preferences with the people we care about and who care about us. This should preferably also include key health care workers, such as a personal GP.

Although the focus of this thesis was on dying at home/place of death, which is easier to measure on a population level than e.g. time spent in a preferred location, a patient centered goal such as days spent at home or in another preferred location may be a more appropriate and realistic goal.[158] The way forward must include both an individual and a system perspective to give dying people a real choice about where they spend the end of life. Health care services should be flexible and tailored to the patients' and family's needs, which will require more focus on advance care planning and systematic ways to identify people who may benefit from palliative care. We also need a population-based strategy for provision of palliative care end of life care for community-dwelling people, taking current and estimated future needs into account.[203, 204] This strategy will have to focus on inadequate policies, shortage of resources, inequity in access to palliative end of life care, lack of guidelines for people not dying from cancer and insufficient education in palliative care.[71, 204] Furthermore, we need organizational changes in our health care system that facilitate collaboration both within primary health care and across health care levels.

Future studies should focus on improving identification of people in need of palliative care, implementation of advance care planning and strategies to improve access to palliative care in primary health care. Strategies for implementation and national quality indicators to measure the quality of palliative end of life care at a population level should be addressed.[205]

8. Errata

Paper 1:

In the Method Section, the listed causes of death read:

> *These were according to the EU Shortlist: 'Cancer' (2.), 'Heart disease' (7.1.2/7.1, 7.2.2, 7.4), 'Chronic pulmonary disease' (8.3.2), 'Kidney disease' (12.1) and 'Neurological disease' (6.1, 6.3).*

The correct causes of death used should read:

> *These were according to the EU Shortlist: 'Cancer' (2.), 'Circulatory disease' (7.), 'Respiratory disease' (8.), 'Kidney disease' (12.1) and 'Neurological disease' (6.1, 6.3).*

Accordingly, in Figure 1, "Heart disease" should be "Circulatory disease" and "Chronic pulmonary disease" should be "Respiratory disease".

We notified BMC Palliative Care about this error and if they would publish this information as an erratum on two occasions but did not receive a reply.

Paper 2:

Figure 1 has "*Long-term care (n=24,986)*" but should read "*Long-term care (n=27,512)*". This has been corrected in Figure 4 in the thesis.

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"We must have perseverance and above all confidence in ourselves. We must believe that we are gifted for something and that this thing must be attained."
Marie Curie

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RESEARCH ARTICLE Open Access

Comparing unplanned and potentially planned home deaths: a population-based cross-sectional study

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Abstract

Background: There is little research on number of planned home deaths. We need information about factors associated with home deaths, but also differences between planned and unplanned home deaths to improve end-of-life-care at home and make home deaths a feasible alternative. Our aim was to investigate factors associated with home deaths, estimate number of potentially planned home deaths, and differences in individual characteristics between people with and without a potentially planned home death.

Methods: A cross-sectional study of all decedents in Norway in 2012 and 2013, using data from the Norwegian Cause of Death Registry and National registry for statistics on municipal health and care services. We defined planned home death by an indirect algorithm-based method using domiciliary care and diagnosis. We used logistic regressions models to evaluate factors associated with home death compared with nursing home and hospital; and to compare unplanned home deaths and potentially planned home deaths.

Results: Among 80,908 deaths, 12,156 (15.0%) were home deaths. A home death was most frequent in 'Circulatory diseases' and 'Cancer', and associated with male sex, younger age, receiving domiciliary care and living alone. Only 2.3% of home deaths were from 'Dementia'. In total, 41.9% of home deaths and 6.3% of all deaths were potentially planned home deaths. Potentially planned home deaths were associated with higher age, but declined in ages above 80 years for people who had municipal care. Living together with someone was associated with more potentially planned home deaths for people with municipal care.

Conclusion: There are few home deaths in Norway. Our estimations indicate that even fewer people than anticipated have a potentially planned home death.

Keywords: Home death, Place of death, Death/epidemiology, Death/statistics and numerical data, Death/classification, Cross-sectional studies, Cause of death, Terminal care, Registries, Retrospective studies

Introduction

Most people wish to spend their last days of life in their own home and die at home [1]. Despite this, the proportion of home deaths in Western countries continues to decline [2]. Exceptions include Canada, the UK and the US, where home deaths have increased the last 15 to 25 years due to implementation of end-of-life programs and policy changes [2–4]. Home deaths increased from 19.3% in 1994 to 29.5% in 2004 in Canada; from 18.3% in 2004 to 20.8% in 2010 in the UK; and from 30.7% in 2000 to 33.5% in 2009 in Medicare beneficiaries aged 66 years and older in the US [2–4].

In Norway, home deaths have been declining, with only 14.3% of deaths taking place at home in 2015 [5, 6]. This is low compared with many other Western countries [7–16]. While home death is not desirable or possible for everyone, we need to know more about who dies at home and influencing factors in order to meet people's preference of dying at home, as well as inform and improve policies. While we know the total number

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of home deaths, this does not describe the proportion of people who wished to die at home or the number of deaths that were planned or facilitated to take place at home. We cannot use registry data to estimate people's preferences, but we can differentiate sudden, unplanned home deaths from home deaths where health and care service utilisation implies that resources were allocated to facilitate a home death.

In this study, our aim was first to describe factors associated with home deaths in Norway, and compare them with deaths in other locations. Secondly, we aimed to estimate how many home deaths may have been planned. Lastly, we wanted to analyse differences in individual characteristics between people where home deaths may have been planned, and people where home death did not appear to have been planned.

Method

Data source

We linked data from the Norwegian Cause of Death Registry (NCoDR) and National registry for statistics on municipal health and care services (IPLOS) covering all 83,434 deaths in Norway in 2012 and 2013. Individuals with missing information about place of death or sex ($n = 2526$) were excluded. The final study sample comprised 80,908 individuals.

Information on causes and place of death are registered in NCoDR [17]. In Norway, the doctor who examines the dead body completes the death certificate. This could be the treating general practitioner or institutional doctor, but also a doctor on night duty. The document is sent to the local county court/police, then to the Chief Municipal Medical Officer, before reaching NCoDR. The registry encompasses all residents, irrespective of whether they die in Norway or abroad, and since 2012 also information on deaths for non-residents. NCoDR has a high degree of coverage and completeness, with medical information on more than 98% of all deaths. Three quality assessments have ranked NCoDR in the second best group with "medium" and "medium-high" quality respectively, and lastly in the best group regarding quality. In all these three studies, the extensive use of unspecific codes served to lower the score. Few validation studies have been conducted [17].

IPLOS is a national registry for statistics on municipal health and care services. Since 2007 it has been the main data source for Norwegian municipal health and care statistics. It is compulsory for municipalities to register information on all persons who apply for or receive municipal health and care services, describing the person's resources, need of assistance and services provided. Hospital admissions are also registered, but not used here due to poor data quality. Updates are continuously registered, and sent to the register annually. Data quality is assessed by comparison with information in other official statistics (KOSTRA – Municipality-State-Reporting) and reports returned to the municipalities [18, 19].

Outcome measures

NCoDR provided information regarding cause of death, place of death, age, sex and place of residence (municipality population and centrality). IPLOS provided information regarding municipal services and household. We divided place of death into four categories: home; nursing home; hospital; other (abroad, under transportation to hospital, other). Cause of death was given by the European Shortlist for Causes of Death (EU Shortlist) [20]. Persons missing cause of death, with diagnoses removed due to privacy or with cause of death main diagnosis groups with a frequency of less than 5% of all deaths were labelled "other". We grouped cause of death into eight categories: 'Infectious/parasitic'; 'Symptoms/signs/ill-defined'; 'External'; 'Cancer' (including uncertain malignancy potential); 'Dementia'; 'Circulatory'; 'Respiratory'; 'Other'. Age at time of death was divided into seven groups (0–39, 40–49, 50–59, 60–69, 70–79, 80–89, 90+ years). Municipality centrality was defined as a municipality's geographic location in relation to a centre with important central functions, where 0 is least central (rural) and 3 is most central (urban) [21]. Domiciliary care was coded 'yes' if an individual received practical help or home nursing at any time 0–90 days before death. Nursing home was coded 'yes' if an individual had a stay of any duration in a nursing home or rehabilitation facility 0–90 days before death. Individuals residing in assisted living accommodations with separate apartments were coded as living alone by IPLOS, while individuals in long-term institutional care were coded as cohabiting [18].

Planned and unplanned home deaths

We created an algorithm to estimate potentially planned and unplanned home deaths (Fig. 1). A home death was defined as unplanned if a person did not receive domiciliary care during the last ninety days before death or if a person who died at home with domiciliary care had cause of death 'Symptoms/signs/ill-defined'. 'Symptoms/signs/ill-defined' were labelled unplanned, since people who have a planned home death would most likely have a known diagnosis of life-threatening disease later appearing as underlying cause of death in the death certificate; as opposed to people dying at home suddenly, but not unexpectedly of an unspecific cause. We defined a home death as potentially planned if a person had domiciliary care and a cause of death among the most likely diagnoses to receive palliative care. These were according to the EU Shortlist: 'Cancer' (2.), 'Heart disease' (7.1.2/7.1, 7.2.2, 7.4), 'Chronic pulmonary disease' (8.3.2),

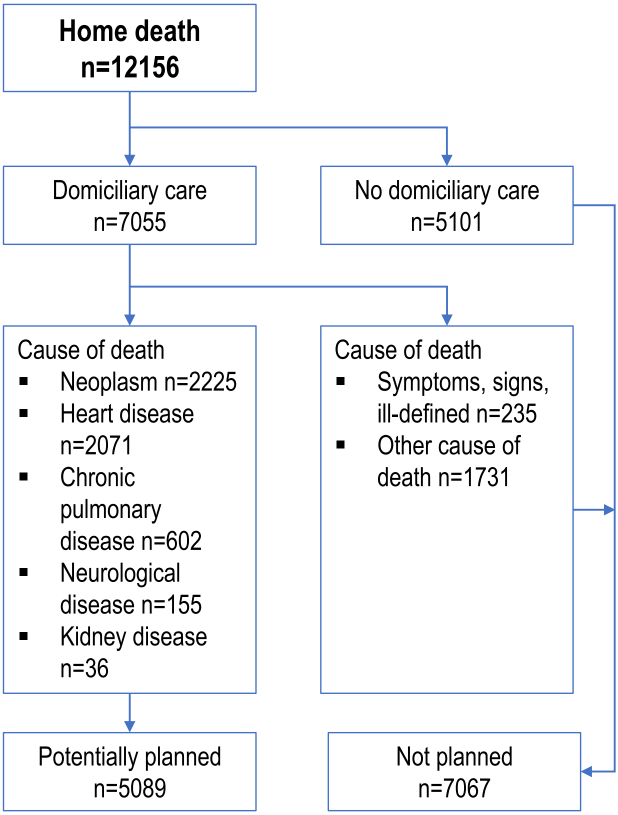

Fig. 1 Algorithm for potentially planned and unplanned home deaths

'Kidney disease' (12.1) and 'Neurological disease' (6.1, 6.3) [20, 22]. Because the majority of people with dementia die in nursing homes, cause of death from 'Dementia' was not included [23]. The remaining home deaths were categorised as unplanned. The age group 0–39 years was given a lower detail level for cause of death than older age groups due to privacy. Cause of death was divided into six categories according to diagnoses most likely to receive palliative care: 'Cancer'; 'Circulatory'; 'Respiratory'; 'Kidney'; 'Neurological'; 'Other'.

Analyses

We used frequency tables and Pearson Chi-square for comparisons. Multinomial logistic regression was used to compare death at home, in nursing home and hospital. Independent variables were sex, age, cause of death, municipality centrality, municipality population and domiciliary care. We did a similar analysis including type of household as explanatory variable in a subpopulation of people who received municipal care at any time (registered in IPLOS). Results are presented as adjusted relative risk ratios (RRRs) with 95% confidence intervals (CI) and *p*-values. xWe used logistic regression to compare potentially planned and unplanned home deaths. Independent variables were sex, age, municipality population, municipality centrality and nursing home stay (model 1). We did a separate analysis for people who received municipal care at any time (registered in IPLOS) with household as an explanatory variable (model 2). Unadjusted and adjusted odds ratios (ORs) with 95% CI and p-values are presented. Significance was accepted at the 5% level ($p < 0.05$) for all analyses. Analyses were conducted with STATA 14 (Stata Corp, College Station, TX).

Results

Describing the population

Among 80,908 deaths 12,156 (15.0%) were classified as home deaths. In total, more women died, with the majority (56.5%) dying in nursing homes (Table 1). While 18.1% of all men died at home, only 12.2% of all women died at home.

Absolute number of home deaths was higher in the older age groups. However, within each age group, home death was more frequent for younger persons (Fig. 2). In people 0–69 years, 26.5% died at home, 19.7% in a nursing home, 44.6% in a hospital and 9.2% in other locations. Only 11.8% of people 70 years or older died at home, while 56.8% died in a nursing home, 30.1% in a hospital and 1.3% in other locations. The most common causes of death were 'Circulatory diseases', 'Cancer', 'Respiratory diseases', 'Infectious diseases' and 'Dementia' (Table 1). 'Circulatory diseases' (34.9%) and 'Cancer' (21.8%) were also the most frequent causes of death within the home death group, while only 2.3% were from 'Dementia'.

A large proportion of deaths had missing information regarding household, largely reflecting people who never received municipal care (Table 1). For those who had services at any time, people living alone (14.2%) died at home more often than those living with others (9.5%). In total, 11.6% had a nursing home stay and 58.0% received domiciliary care in the last 90 days before dying at home. Of all persons who had a nursing home stay in the last 90 days before death, 3.0% died at home, while 17.9% of those receiving domiciliary care died at home.

Comparing home deaths with deaths in nursing homes and hospitals

Multinomial regression showed that women had a lower relative risk than men for dying at home compared with nursing home (Table 2). We found an age gradient with more home deaths in younger age groups, except for people aged 90 years or older who had a higher relative risk for dying at home than in a hospital, but highest relative risk of dying in a nursing home. People who died from 'Cancer' and 'Respiratory disease' had lower relative risk of home death than 'Circulatory disease' compared with nursing home and hospital. People with 'Dementia' had higher relative risk of dying in nursing homes than home, but lower relative risk of dying in hospitals. Recipients of domiciliary care had higher relative risk of dying at home than in nursing homes or hospitals. A similar regression analysis with only persons who at any time had received municipal care (registered in IPLOS), including household as independent variable, did not alter main findings, but showed that people living with others had lower relative risk of home death compared with death in nursing home (RRR 0.77, 95% CI 0.73, 0.82) and hospital (RRR 0.90, 95% CI 0.87, 0.94).

Comparing potentially planned and unplanned home deaths

According to our algorithm for estimating potentially planned and unplanned home deaths (Fig. 1), 56.1% of home deaths and 8.4% of all deaths were potentially planned home deaths when we included everyone with domiciliary care but not 'Symptoms/signs/ill-defined' causes of death. In the full algorithm, including cause of death, 41.9% of home deaths and 6.3% of all deaths were potentially planned home deaths. Men had a higher proportion of both potentially planned and unplanned home deaths than women (Table 3). In people aged 50 years or older 44.5% of home deaths were potentially planned, but only 15.7% in those younger than 50 years. Living alone was more frequent in both potentially planned and unplanned home deaths, but more than half of unplanned home deaths had missing information regarding household, making comparisons uncertain. While 84.0% of 'Cancer' home deaths were potentially planned, this constituted only 10.2% of all 'Cancer' deaths. The proportion of potentially planned home deaths among all home deaths and total number of deaths for each diagnosis were 76.4% and 8.5% in 'Neurological disease', 69.2% and 7.4% in 'Renal disease', 63.2% and 7.3% in 'Respiratory disease' and 48.8% and 8.3% in 'Circulatory disease', respectively. Moreover, 72.1% of all home deaths and 12.9% of all deaths were potentially planned in recipients of domiciliary care.

Table 4 compares two regression models of potentially planned versus unplanned home deaths. In model 1, including all home deaths, women had higher odds than men for having a potentially planned home death, but in model 2, which was restricted to include people who at any time had received municipal care, women had lower odds for having a potentially planned home death. Higher age was associated with more potentially planned home deaths, but in model 2 ages 60–79 years had the highest odds, with declining odds in older age groups. Municipalities with less than 50,000 inhabitants were consistently associated with more potentially planned home deaths, of which municipalities with 5001–10,000 inhabitants had the highest odds. A nursing home stay during the last 90 days before death was associated with higher odds for a potentially planned home death in model 1, but had lower odds in model 2. Living together with someone increased the odds for a potentially planned home death in model 2.

Discussion

Main findings

This population-based registry study showed that home death in Norway was most frequent in 'Circulatory disease' and 'Cancer', and associated with male

Table 1 Distribution of sociodemographic factors and municipal healthcare services by place of death in Norway 2012–2013.*

	Place of death									
	Home		Nursing home		Hospital		Other[a]		Total	
	n	%	n	%	n	%	n	%	n	%
All	12,156	100	39,345	100	26,962	100	2445	100	80,908	100
Sex										
Female	5175	42.6	23,904	60.8	12,613	46.8	598	24.5	42,290	52.3
Male	6981	57.4	15,441	39.2	14,349	53.2	1847	75.5	38,618	47.7
Age (years)										
0–39	549	4.5	70	0.2	796	3.0	426	17.4	1841	2.3
40–49	550	4.5	191	0.5	724	2.7	263	10.8	1728	2.1
50–59	1249	10.3	776	2.0	1877	7.0	389	15.9	4291	5.3
60–69	2381	19.6	2477	6.3	4553	16.9	564	23.1	9975	12.3
70–79	2538	20.9	5917	15.0	6212	23.0	386	15.8	15,053	18.6
80–89	3293	27.1	16,595	42.2	9134	33.9	338	13.8	29,360	36.3
90+	1596	13.1	13,319	33.9	3666	13.6	79	3.2	18,660	23.1
Cause of death										
Infectious/parasitic	1077	8.9	3562	9.1	2131	7.9	264	10.8	7034	8.7
Cancer	2648	21.8	10,728	27.3	8431	31.3	106	4.3	21,913	27.1
Dementia	274	2.3	4951	12.6	211	0.8	11	0.5	5447	6.7
Circulatory	4244	34.9	11,341	28.8	8692	32.2	727	29.7	25,004	30.9
Respiratory	952	7.8	4078	10.4	3117	11.6	65	2.7	8212	10.2
Symptoms/signs/ill-defined	603	5.0	343	0.9	39	0.1	340	13.9	1325	1.6
External causes	754	6.2	416	1.1	788	2.9	657	26.9	2615	3.2
Other	1604	13.2	3926	10.0	3553	13.2	275	11.2	9358	11.6
Household										
Cohabiting	3231	26.6	21,727	55.2	8692	32.2	240	9.8	33,890	41.9
Living alone	4038	33.2	15,341	39.0	8825	32.7	336	13.7	28,540	35.3
Missing[b]	4887	40.2	2277	5.8	9445	35.0	1869	76.4	18,478	22.8
Municipality population										
0–2000	425	3.5	1472	3.7	767	2.8	123	5.0	2787	3.4
2001–5000	1460	12.0	4733	12.0	2508	9.3	271	11.1	8972	11.1
5001–10,000	1795	14.8	5579	14.2	3381	12.5	354	14.5	11,109	13.7
10,001–50,000	4840	39.8	14,844	37.7	10,504	39.0	903	36.9	31,091	38.4
50,001-	3603	29.6	12,632	32.1	9683	35.9	746	30.5	26,664	33.0
Missing[b]	33	0.3	85	0.2	119	0.4	48	2.0	285	0.4
Municipality centrality[c]										
Least central	1531	12.6	5129	13.0	2850	10.6	346	14.2	9856	12.2
Less central	858	7.1	2664	6.8	1859	6.9	201	8.2	5582	6.9
Somewhat central	2431	20.0	7651	19.4	4954	18.4	393	16.1	15,429	19.1
Central	7303	60.1	23,816	60.5	17,180	63.7	1457	59.6	49,756	61.5
Missing[b]	33	0.3	85	0.2	119	0.4	48	2.0	285	0.4
Nursing home[d]										
Yes	1448	11.9	39,945	100.0	7945	29.5	139	5.7	48,877	60.4
No	10,708	88.1	0	0.0	19,017	70.5	2306	94.3	32,031	39.6

Table 1 Distribution of sociodemographic factors and municipal healthcare services by place of death in Norway 2012–2013.* *(Continued)*

	Place of death									
	Home		Nursing home		Hospital		Other[a]		Total	
	n	%	n	%	n	%	n	%	n	%
Domiciliary care[d]										
Yes	7055	58.0	16,455	41.8	15,456	57.3	479	19.6	39,445	48.8
No	5101	42.0	22,890	58.2	11,506	42.7	1966	80.4	41,463	51.2

*Pearson chi-square test: $p < 0.001$ for all categories

[a] Other place of death includes abroad, under transportation to hospital, other specified

[b] Not included in statistical analysis

[c] Classification based on geographical distance to centre with higher functions

[d] Service any time in the period 0–90 days before death

sex, younger age, receiving domiciliary care and living alone. In total, 41.9% of home deaths and 6.3% of all deaths were potentially planned. Potentially planned home deaths were associated with higher age, but declined in ages above 80 years for people who had municipal care. Living together with someone was associated with more potentially planned home deaths for people with municipal care.

Strengths and limitations

To our knowledge, this is the first study to estimate number of potentially planned home deaths by using population-based registry data. The use of routinely collected data, minimises the burden on patients and caregivers, associated with primary data collection in end-of-life care context [24]. The use of death certificates is similar across countries and comparable. NCoDR provides cause of death for more than 98% of all deaths in Norway, but has high use of unspecific cause of death codes increasing the risk of misclassification. Additionally, few diagnoses are verified by autopsy [17]. The study accounts for domiciliary care and nursing home admissions prior to death, but it is a limitation that we do not have information regarding hospital admissions. A methodological limitation is that we have no exact data on planned home deaths, but use an indirect approach by an algorithm. However, there is no registry based information source available as an alternative. A limitation for some analyses is that information regarding whether a person lived alone or together with others was only available for people who had received municipal care. Our definition of a potentially planned home death may also have led to deaths from acute illness being classified as potentially planned. Moreover, we cannot exclude that persons with other

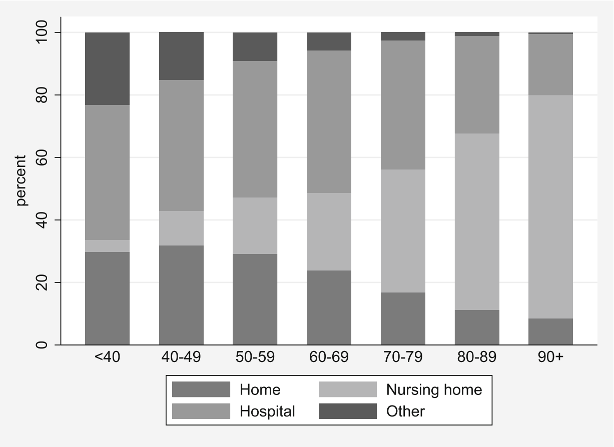

Fig. 2 Distribution of place of death by age groups

Table 2 Adjusted relative risk ratio (RRR) for death at home versus nursing home, and home versus hospital[a]

	Home versus nursing home[a]			Home versus hospital[a]		
	Adjusted RRR	CI	p	Adjusted RRR	CI	p
Sex						
Female	0.67	0.64, 0.71	< 0.001	0.97	0.93, 1.02	0.223
Male	Ref.			Ref.		
Age						
0–39	49.76	38.34, 64.58	< 0.001	2.21	1.94, 2.51	< 0.001
40–49	19.77	16.55, 23.61	< 0.001	2.61	2.31, 2.96	< 0.001
50–59	11.71	10.55, 12.99	< 0.001	2.38	2.18, 2.60	< 0.001
60–69	7.20	6.68, 7.75	< 0.001	1.91	1.78, 2.04	< 0.001
70–79	2.71	2.55, 2.89	< 0.001	1.32	1.24, 1.41	< 0.001
80–89	Ref.			Ref.		
90+	0.55	0.52, 0.59	< 0.001	1.11	1.03, 1.19	0.006
Cause of death						
Infectious and parasitic diseases	0.95	0.88, 1.04	0.267	1.03	0.95, 1.12	0.461
Cancer	0.22	0.21, 0.24	< 0.001	0.48	0.45, 0.51	< 0.001
Dementia	0.23	0.20, 0.26	< 0.001	3.18	2.64, 3.82	< 0.001
Circulatory	Ref.			Ref.		
Respiratory	0.51	0.47, 0.56	< 0.001	0.60	0.55, 0.65	< 0.001
Symptoms/signs/ill-defined	3.84	3.29, 4.48	< 0.001	32.21	23.22, 44.71	< 0.001
External causes	1.92	1.66, 2.21	< 0.001	1.55	1.38, 1.74	< 0.001
Other	0.58	0.54, 0.63	< 0.001	0.76	0.71, 0.82	< 0.001
Municipality population						
0–2000	1.11	0.97, 1.28	0.135	1.67	1.45, 1.93	< 0.001
2001–5000	1.13	1.03, 1.24	0008	1.73	1.58, 1.93	< 0.001
5001–10,000	1.11	1.02, 1.20	0.014	1.54	1.42, 1.66	< 0.001
10,001–50,000	1.06	1.00, 1.13	0.033	1.30	1.23, 1.37	< 0.001
50,001-	Ref.			Ref.		
Municipality centrality						
Least central	0.95	0.87, 1.03	0.227	0.94	0.86, 1.03	0.198
Less central	1.07	0.97, 1 17	0.190	0.90	0.82, 0.99	0.024
Somewhat central	1.02	0.96, 1.09	0.465	1.01	0.95, 1.07	0.839
Central	Ref.			Ref.		
Domiciliary care						
Yes	2.70	2.58, 2.83	< 0.001	1.35	1.29, 1.42	< 0.001
No	Ref.			Ref.		

[a] Multinomial logistic regression with place of death as dependent variable. Number of observations 78,226

diagnoses than included in our definition may have had planned home deaths.

Few potentially planned home deaths

Our data cannot give information regarding a person's preference for dying at home. However, we will argue that our estimation of potentially planned home deaths in Norway is a valid indication. Planned home death is not feasible without the support of domiciliary care and not probable when cause of death is unknown. Even if there is no preference of dying at home, domiciliary care in itself signals facilitation of more time at home and increases the probability of dying at home [25]. Thus, the highest proportion of home deaths that was not random, and could potentially have been planned, was 56.1% or 8.4% of all deaths in our model. However, it is likely that

Table 3 Comparing potentially planned home deaths with unplanned home deaths and all deaths[a]

	Potentially planned home death		Unplanned home death			All deaths	
	n	%	n	%	*p*	n	%
All	5089	100	7067	100		80,908	100
Sex					< 0.001		
Female	2458	48.3	2717	38.5		42,290	52.3
Male	2631	51.7	4350	61.5		38,618	47.7
Age (years)					< 0.001		
0–39	60	1.2	489	6.9		1841	2.3
40–49	113	2.2	437	6.2		1728	2.1
50–59	367	7.2	882	12.5		4291	5.3
60–69	887	17.4	1494	21.1		9975	12.3
70–79	1115	21.9	1423	20.1		15,053	18.6
80–89	1673	32.9	1620	22.9		29,360	36.3
90+	874	17.2	722	10.2		18,660	23.1
Cause of death[b]					< 0.001		
Cancer	2225	43.7	423	6.0		21,913	27.1
Circulatory	2071	40.7	2173	30.7		25,004	30.9
Respiratory	602	11.8	350	5.0		8212	10.2
Neurological	155	3.0	48	0.7		1819	2.2
Renal	36	0.7	16	0.2		489	0.6
Other	0	0.0	4057	57.4		23,471	29.0
Household					< 0.001		
Cohabiting	2273	44.7	958	13.6		33,890	41.9
Living alone	2366	46.5	1672	23.7		28,540	35.3
Missing[c]	450	8.8	4437	62.8		18,478	22.8
Municipality population					< 0.001		
0–2000	175	3.4	250	3.5		2787	3.4
2001–5000	651	12.8	809	11.4		8972	11.1
5001–10,000	826	16.2	969	13.7		11,109	13.7
10,001–50,000	2092	41.1	2748	38.9		31,091	38.4
50,001-	1337	26.3	2266	32.1		26,664	33.0
Missing[c]	8	0.2	25	0.4		285	0.4
Municipality centrality					< 0.001		
Least central	647	12.7	884	12.5		9856	12.2
Less central	377	7.4	481	6.8		5582	6.9
Somewhat central	1071	21.0	1360	19.2		15,429	19.1
Central	2986	58.7	4317	61.1		49,756	61.5
Missing[c]	8	0.2	25	0.4		285	0.4
Nursing home[d]					< 0.001		
Yes	860	16.9	549	7.8		46,638	57.6
No	4229	83.1	6518	92.2		34,270	42.2
Domiciliary care[d]					< 0.001		
Yes	5089	100.0	1966	27.8		39,445	48.8
No	0	0.0	5101	72.2		41,463	51.2

[a] *P* Pearson chi-square test for planned and unplanned home deaths

[b] Cause of death was divided into five categories according to diagnoses most likely to receive palliative care, the rest were labelled other

[c] Not included in statistical analysis

[d] Service any time in the period 0–90 days before death

Table 4 Odds ratio (OR) for potentially planned home death compared with unplanned home death [a]

	Unadjusted			Model 1			Model 2		
	OR	CI	*p*	Adjusted OR	CI	*p*	Adjusted OR	CI	*p*
Sex									
Female	1.50	(1.39, 1.61)	< 0.001	1.29	(1.20, 1.40)	< 0.001	0.90	(0.81, 0.99)	0.039
Male	Ref.			Ref.			Ref.		
Age									
0–39	0.12	(0.09, 0.16)	< 0.001	0.14	(0.11, 0.18)	< 0.001	0.19	(0.13, 0.26)	< 0.001
40–49	0.25	(0.20, 0.31)	< 0.001	0.29	(0.23, 0.37)	< 0.001	0.41	(0.31, 0.54)	< 0.001
50–59	0.40	(0.35, 0.46)	< 0.001	0.46	(0.40, 0.53)	< 0.001	0.71	(0.59, 0.87)	0.001
60–69	0.57	(0.52, 0.64)	< 0.001	0.65	(0.58, 0.72)	< 0.001	1.26	(1.07, 1.48)	0.005
70–79	0.76	(0.68, 0.84)	< 0.001	0.82	(0.74, 0.91)	< 0.001	1.32	(1.14, 1.52)	< 0.001
80–89	Ref.			Ref.			Ref.		
90+	1.17	(1.04, 1.32)	0.009	1.10	(0.97, 1.25)	0.122	0.80	(0.70, 0.92)	0.002
Municipality population									
0–2000	1.19	(0.97, 1.46)	0.102	1.29	(1.02, 1.64)	0.032	1.40	(1.01, 1.95)	0.043
2001–5000	1.36	(1.21, 1.54)	< 0.001	1.36	(1.17, 1.58)	< 0.001	1.40	(1.15, 1.71)	0.001
5001–10,000	1.44	(1.29, 1.62)	< 0.001	1.46	(1.28, 1.67)	< 0.001	1.47	(1.22, 1.75)	< 0.001
10,001–50,000	1.29	(1.18, 1.41)	< 0.001	1.27	(1.15, 1.40)	< 0.001	1.27	(1.12, 1.44)	< 0.001
50,001-	Ref.			Ref.			Ref.		
Municipality centrality									
Least central	1.06	(0.95, 1.18)	0.321	0.85	(0.74, 0.99)	0.031	0.94	(0.78, 1.15)	0.570
Less central	1.13	(0.98, 1.31)	0.086	0.99	(0.85, 1.16)	0.923	1.02	(0.82, 1.26)	0.868
Somewhat central	1.14	(1.04, 1.25)	0.006	0.99	(0.89, 1.10)	0.877	0.99	(0.86, 1.14)	0.904
Central	Ref.			Ref.			Ref.		
Nursing home									
Yes	2.44	(2.18, 2.73)	< 0.001	2.00	(1.78, 2.25)	< 0.001	0.78	(0.68, 0.88)	< 0.001
No	Ref.			Ref.			Ref.		
Household									
Cohabiting	1.68	(1.52, 1.85)	< 0.001				1.62	(1.46, 1.80)	< 0.001
Living alone	Ref.						Ref.		

[a] unadjusted, adjusted model 1 for all home deaths ($n = 12{,}123$) and adjusted model 2 for persons who had received municipal care ($n = 7261$)

the proportion of potentially planned home deaths is even lower in Norway than our final estimation (41.9% of home deaths and 6.3% of all deaths), as palliative care is mostly given to people with cancer [22, 26].

Most research regarding planned home deaths are interventions trying to enable more home deaths, with little data on the actual rate of planned home deaths before the intervention [27]. We found that only 49% of home deaths from 'Circulatory disease' were potentially planned, while 84% of home deaths from 'Cancer' were potentially planned. This indicates a large proportion of sudden or unexpected home deaths from 'Circulatory disease', but could also indicate inequality between these groups in recognition of palliative care needs [28, 29].

Comparison with previous research

Previous studies have shown that the proportion of home deaths is associated with low functional status, preferences on place of death, home care and its intensity, living with relatives, extended family support, home palliative care, not living in urban areas, higher socio-economic status and being male [8, 14, 16, 25]. Other factors influencing home death are culture, ethnicity and number of hospital and nursing home beds. The relationship with age is more complicated [8, 14, 16, 25].

We found that living alone was associated with more home death. This should be interpreted with caution as we had a large proportion of missing data, but could indicate a large proportion of unexpected home deaths for people living alone. However, in a subpopulation of people who had received municipal care, potentially planned home deaths were associated with living together with someone.

There is no consensus definition on rurality, but there is consistency in associations with place of death across definitions [30]. We did not find any association with our definition of rural areas [21], but municipalities with fewer inhabitants were associated with more home death compared to hospital and also with more potentially planned home deaths. This indicates that other factors than travelling distance to hospitals influence proportion of home deaths. Home nursing coverage could be a contributing factor, as smaller municipalities in Norway have better home nursing coverage than larger municipalities. The largest cities have higher coverage of long-term care in institutions and the lowest coverage of home nursing, which could shift end-of-life care to nursing homes instead of home [31].

Our results also showed that fewer women died at home than men. The association was significant when compared to nursing home, similar to a Swedish study [9]. A possible explanation could be that women care for their spouses and live longer, but the association was present also after adjusting for age and living together with someone. Another explanation could be that men have more sudden and unexpected home deaths, as only men had home deaths from external causes of death or symptoms/signs/ill-defined and more unplanned home deaths from circulatory disease. Still, men had higher odds of a potentially planned home death in the subpopulation who had received municipal care.

Like many other countries, Norway has experienced declining home death rates and a shift from hospital to nursing home deaths [6, 8, 14] . This is partly due to population aging but also end-of-life care policy [2–4, 6]. Incongruence between preferred and actual place of death is common, especially for people with non-malignant disease [29]. Dying in their preferred place is considered a quality indicator of care, and should together with evidence that a majority of people prefer to die at home, be reflected in future planning of palliative care services [1, 32].

Transitions in the last phase of life is another important factor to consider when evaluating quality of end-of-life care. Transitions in the last months and days before death are common, with more than half of dying people having at least one transition [33, 34]. Transitions are shown to be more common in home-dwelling people, where about half have a final transition from home to hospital [33, 34]. Groff et al. found an inverse relationship between number of days in domiciliary care and days spent at home in the last six months before death, interpreted as doing more of one thing led to doing more in other areas as well, and did not necessarily improve patient-centred goals [35]. Although home death will never be a goal or possible for all dying people, a more person-centred goal like "days spent at home" could change the perspective of both the dying person and caregivers and lead to increased time spent at home in the final phase of life, and together with palliative homecare reduce symptom burden and increase chances of home death according to the person's own wishes [27, 36, 37].

Conclusions

This registry based study from Norway shows that home death is relatively infrequent, and by an indirect algorithm-based definition, we have shown that less than half of them are potentially planned home deaths. Future research should investigate how many deaths that are actually planned to take place at home, and the achievement of this goal. There is also a need to understand the transitions in the last phase of life and whether the place of death corresponds to the patients' wish, and how palliative homecare influences such outcomes.

Abbreviations

EU Shortlist: European Shortlist for Causes of Death; RRR: Relative risk ratio; IPLOS: National registry for statistics on municipal health and care services; NCoDR: Norwegian Cause of Death Registry

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Availability of data and materials

Data in this study was accessed through linkage of data from the Norwegian Cause of Death Registry at the Norwegian Institute of Public Health (https://www.fhi.no) and IPLOS at the Norwegian Directorate of Health (https://helsedirektoratet.no/iplos-registeret). Release of data to researchers requires approval from the Regional Committee for Medical and Health Research Ethics (https://helseforskning.etikkom.no/), the Norwegian Data Protection Authority through the Norwegian Centre for Research Data (http://www.nsd.uib.no) and from the respective registries.

Authors' contributions

CK performed study procedures, analysis of data and was responsible for drafting and editing of the manuscript. SH participated in the conception and design of the study, interpretation of the data, and took part in drafting and editing the manuscript. HS participated in the analysis and interpretation of the data and revising the manuscript. BSH participated in the conception and design of the study and revising the manuscript. EF participated in the conception and design of the study and revising the manuscript. All authors read and approved the final manuscript.

Ethics approval and consent to participate

The study was approved by the Regional Committee for Medical and Health Research Ethics North (2014/2308) and the Norwegian Data Protection Authority (15/00450–2/CGN, 17/00341–3/SBO). Informed consent was not possible.

Competing interests
The authors declare that they have no competing interests.

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RESEARCH ARTICLE Open Access

Associations between home deaths and end-of-life nursing care trajectories for community-dwelling people: a population-based registry study

Camilla Kjellstadli[1,2*], Ling Han[2], Heather Allore[2,3], Elisabeth Flo[4], Bettina S. Husebo[1,5] and Steinar Hunskaar[1,6]

Abstract

Background: Few studies have estimated planned home deaths compared to actual place of death in a general population or the longitudinal course of home nursing services and associations with place of death. We aimed to investigate trajectories of nursing services, potentially planned home deaths regardless of place of death; and associations of place of death with potentially planned home deaths and nursing service trajectories, by analyzing data from the last 90 days of life.

Methods: A retrospective longitudinal study with data from the Norwegian Cause of Death Registry and National registry for statistics on municipal healthcare services included all community-dwelling people who died in Norway 2012–2013 ($n = 53{,}396$). We used a group-based trajectory model to identify joint trajectories of home nursing (hours per week) and probability of a skilled nursing facility (SNF) stay, each of the 13 weeks leading up to death. An algorithm estimated potentially planned home deaths. We used a multinomial logistic regression model to estimate associations of place of death with potentially planned home deaths, trajectories of home nursing and short-term SNF.

Results: We identified four home nursing service trajectories: no (46.5%), accelerating (7.6%), decreasing (22.1%), and high (23.5%) home nursing; and four trajectories of the probability of a SNF stay: low (69.0%), intermediate (6.7%), escalating (15.9%), and increasing (8.4%) SNF. An estimated 24.0% of all deaths were potentially planned home deaths, of which a third occurred at home. Only high home nursing was associated with increased likelihood of a home death (adjusted relative risk ratio (aRRR) 1.29; CI 1.21–1.38). Following any trajectory with elevated probability of a SNF stay reduced the likelihood of a home death.

Conclusions: We estimated few potentially planned home deaths. Trajectories of home nursing hours and probability of SNF stays indicated possible effective palliative home nursing for some, but also missed opportunities of staying at home longer at the end-of-life. Continuity of care seems to be an important factor in palliative home care and home death.

Keywords: Home care, Epidemiology, Primary care, Terminal care

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Background

Like Japan, Germany, Italy and Portugal, Norway has declining home death rates, with only 13.3% home deaths in 2016 [1–6]. Most people, however, express a wish to receive end-of-life care at home or to die at home [7]. We recently estimated that only about half of the registered home deaths in Norway may have been planned to take place at home [8]. Currently, no studies have estimated the number of potentially planned home deaths in comparison to actual place of death in a general population.

Specialized community-based palliative homecare benefits patients by increasing the likelihood of dying at home [9–11], but is unavailable to most dying people [12]. Specialized palliative care is organized within hospitals and mainly focused on cancer patients [13]. Norway has universal healthcare, and municipalities are required to provide home nursing services and skilled-nursing facility care to its inhabitants. Services are available based on needs, and provided to almost 7% of the population. Home nursing services are free to the patient, while skilled nursing facility (SNF) stays have a deductible based on income. Most SNFs offer some palliative care [13]. Community-dwelling people may experience various patterns of home nursing services and short-term SNF stays before death. Few have investigated the longitudinal course of home nursing services and whether it is associated with place of death [14, 15]. Insight into relationships of these services for community-dwelling patients on place of death may inform policy for end-of-life home-based services.

We aimed to 1) investigate trajectories of nursing services in the last 90 days of life; 2) estimate how many deaths that potentially could have been planned home deaths, regardless of actual place of death; and 3) investigate associations between place of death, potentially planned home deaths and nursing service trajectories, by analyzing data from the last 90 days of life.

Methods

Study design and data sources

We linked data from the Norwegian Cause of Death Registry (NCoDR) and the National register for statistics on municipal healthcare services (IPLOS) and included all deceased individuals in Norway in 2012–2013 with known place of death and sex ($n = 80{,}908$) (Fig. 1). We excluded persons in long-term SNFs ($n = 27{,}512$) to get a study population of community-dwelling people. NCoDR provided information on cause and place of death, age, sex, and municipality centrality. To ensure privacy, people 0–39 years were given fewer details for the cause of death. IPLOS provided information on cohabitation and municipal nursing and care services 0–90 days before death. Information on cohabitation was missing for persons never registered in IPLOS.

Measurements

Home nursing and short-term SNF stays

Home nursing includes specific nursing procedures, such as personal care and daily tasks, drug administration, food preparation and general palliative care. Estimates of the amount of home nursing hours were based on service decisions provided as mean hours

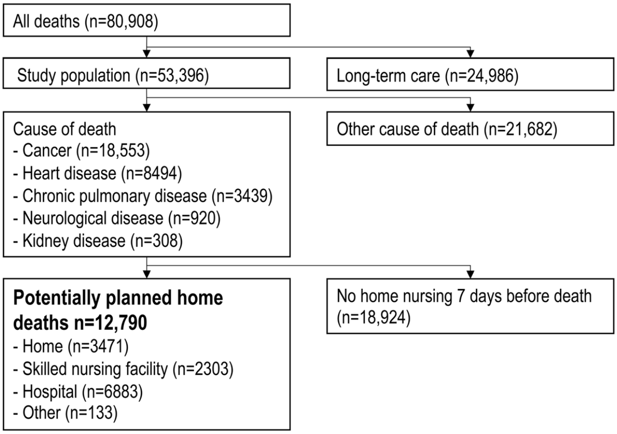

Fig. 1 Algorithm to indirectly assess deaths that were potentially planned to occur at home, regardless of actual location of death. Deaths in all locations were assessed (home, hospital, skilled nursing facility, other). Step 1: Cause of death associated with palliative care (y/n). Step 2: Received home nursing services 7 days before death (y/n)

per week (hrs/wk) for each of the 13 weeks (0–90 days) leading up to death. People with no home nursing had 0 hrs/wk. and maximum value indicating care 24/7 was 168 hrs/wk. Short-term SNF stays were based on service decisions and coded as occurring or not for each of the 13 weeks leading up to death.

Potentially planned home deaths

Based on previous research we developed an algorithm to indirectly estimate deaths that could have been planned to occur at home, regardless of actual location of death (Fig. 1) [8]. A potentially planned home death was considered probable for people with a cause of death most likely to receive palliative care. According to the European Shortlist for Causes of Death, this was 'Cancer' (2.), 'Heart disease' (7.0/7.1.2/7.2/7.4; excluding acute myocardial infarction), 'Chronic pulmonary disease' (8.0/8.3/8.3.1/8.3.2/8.4), 'Kidney disease' (12.1) or 'Neurological disease' (6.0/6.1/6.3) [16, 17]. Dementia was not included as almost all Norwegians with dementia die in long-term SNFs [8, 18]. Receiving any home nursing 7 days before death was considered a requirement for a planned home death. Thus, in our algorithm, a potentially planned home death required a "yes" to both the following steps of inquiry: Step 1: Was the person's cause of death associated with palliative care? (y/n), Step 2: Did the person receive home nursing 7 days before death? (y/n). The remaining deaths were categorized as unplanned to take place at home, hereafter 'unplanned'. To test how sensitive the estimated number of potentially planned home deaths were to changes in the home nursing criterium, we evaluated the effects of replacing receipt of home nursing within day seven with receipt of home nursing 14 days before death. As circumstances may have led to a transition to another location before death, we used the above algorithm to assess deaths in all locations; home, SNF, hospital and other.

Covariates

Cause of death was divided into categories based on diagnoses used to define potentially planned home deaths: 'Cancer'; 'Heart; 'Pulmonary'; 'Kidney'; 'Neurological'. All other causes were labeled 'Other'. We defined seven age-groups; 0–39 years, 10-year intervals up to 89 years, and ≥ 90 years. Municipality centrality was defined as a municipality's geographic location in relation to a center with important central functions, where 0 is least central and 3 most central [19].

Statistical analyses

Decedent characteristics were presented as frequency and percentages with differences within place of death tested using Chi-square tests.

We used a group-based, dual-trajectory model to identify parallel trajectories of home nursing and short-term SNF stays in the last 13 weeks of life by means of a Stata Traj plugin [20, 21]. This is a semiparametric finite mixture model for longitudinal data using a maximum likelihood method [21]. Hours of home nursing trajectories were modeled using a censored normal distribution after a log transformation ($\log_{10}$(home nursing hrs/wk. + 0.1)) to normalize. We modeled probability of a SNF stay each week with a Bernoulli distribution. We modeled each outcome separately, then jointly. Model selection was performed by adding one trajectory at a time followed by varying higher-order growth terms until an optimal fit was achieved based on the Bayesian Information Criterion, average posterior probability of assignment (PPA) (≥0.9 considered excellent fit), odds of correct classification, the proportion with PPA < 0.7 (indicated poor fit), and differences between predicted and observed group proportions [21]. Group size of 5% was considered a minimum.

Next, we used a multinomial logistic regression to estimate associations of place of death with potentially planned home deaths, trajectories of home nursing and short-term SNF. Adjusted relative risk ratio (aRRR) and their 95% CI was estimated after, adjusting for sex, age and municipality centrality as potential confounding factors. Living with others was assessed as a possible confounder in the population with information on cohabitation (registered in IPLOS, $n = 35{,}600$), without any indication of this being the case. All analyses were conducted with Stata version 15 (Stata Corp, College Station, TX). Two-sided p-values < 0.05 were considered statistically significant.

Results

Characteristics of the population

In our population of community-dwelling people, 54.1% were men and 85.8% were ≥ 60 years (Table 1). The most common causes of death were cancer (34.8%) and heart disease (15.9%). Almost half died in hospitals, nearly a third in SNFs, and another fifth at home. A higher proportion of men died at home and in hospitals, while women died more frequently in SNF (Table 1). As expected, people ≥80 years had a higher proportion of SNF deaths. Nearly a fifth of home deaths occurred in people < 60 years. While over half of SNF deaths were from cancer, they constituted only a fifth of home deaths. Conversely, deaths from heart disease were more common at home. Ninety days before death 4.9% had a short-term SNF stay, 42.4% received home nursing services, 8.6% received other municipal services, and 44.1% received no municipal services.

Joint trajectories of home nursing services and probability of SNF stays

We identified four trajectories of home nursing (hrs/wk) and four trajectories of the probability of being in a SNF

Table 1 Characteristics of 53,396 home-dwelling people who died in Norway 2012–2013 by place of death

	Home		Nursing home		Hospital		Other[a]	
	n	%	n	%	n	%	n	%
Overall population	11,867	22.2	14,895	27.9	24,241	45.4	2393	4.5
Sex								
Female	4985	42.0	7827	52.6	11,136	45.9	566	23.7
Male	6882	58.0	7068	47.5	13,105	54.1	1827	76.4
Age (years)								
0–39	548	4.6	63	0.4	789	3.3	426	17.8
40–49	549	4.6	165	1.1	719	3.0	263	11.0
50–59	1243	10.5	604	4.1	1854	7.7	389	16.3
60–69	2372	20.0	1860	12.5	4395	18.1	561	23.4
70–79	2505	21.1	3242	21.8	5772	23.8	378	15.8
80–89	3171	26.7	5855	39.3	7827	32.3	314	13.1
90+	1479	12.5	3106	20.9	2885	11.9	62	2.6
Cause of death								
Heart	2456	20.7	1933	13.0	3704	15.3	401	16.8
Cancer	2624	22.1	7629	51.2	8198	33.8	102	4.3
Pulmonary	738	6.2	783	5.3	1874	7.7	44	1.8
Neurological	234	2.0	242	1.6	428	1.8	16	0.7
Kidney	51	0.4	101	0.7	152	0.6	4	0.2
Other	5764	48.6	4207	28.2	9885	40.8	1826	76.3
Household[b]								
Cohabiting	3067	25.8	6390	42.9	7125	29.4	214	8.9
Living alone	3920	33.0	6906	46.4	7741	31.9	314	13.1
Potentially planned home death								
Yes	3471	29.3	2303	15.5	6883	28.4	133	5.6
No	8396	70.8	12,592	84.5	17,358	71.6	2260	94.4
Home nursing trajectory								
No	6055	51.0	4921	33.0	11,846	48.9	2036	85.1
Accelerating	872	7.4	1144	7.7	2118	8.7	34	1.4
Decreasing	1536	12.9	5653	38.0	4413	18.2	159	6.6
High	3404	28.7	3177	21.3	5864	24.2	164	6.9
SNF trajectory								
Low	10,797	91.0	4204	28.2	19,635	81.0	2320	97.0
Increasing	174	1.5	3462	23.2	901	3.7	20	0.8
Intermediate	601	5.1	1082	7.3	1824	7.5	30	1.3
Escalating	295	2.5	6147	41.3	1881	7.8	23	1.0

Note. Pearson chi-square test comparing place of death: $p < 0.001$ for all categories

[a] Other place of death includes abroad, under transportation to hospital, other specified

[b] 17,719 missing household

each week. The model, with quadratic growth terms, was judged to provide an excellent fit to the data, with PPA ≥0.94 for all trajectories, and clinically interpretable. The four trajectories for home nursing services are shown in Fig. 2 (A1-A4):

A1. The largest group of decedents (46.5%) followed a trajectory of no home nursing services, hereafter called “no home nursing”.

A2. 7.9% had accelerating home nursing services starting 9 weeks before death, reaching a median of 1.7

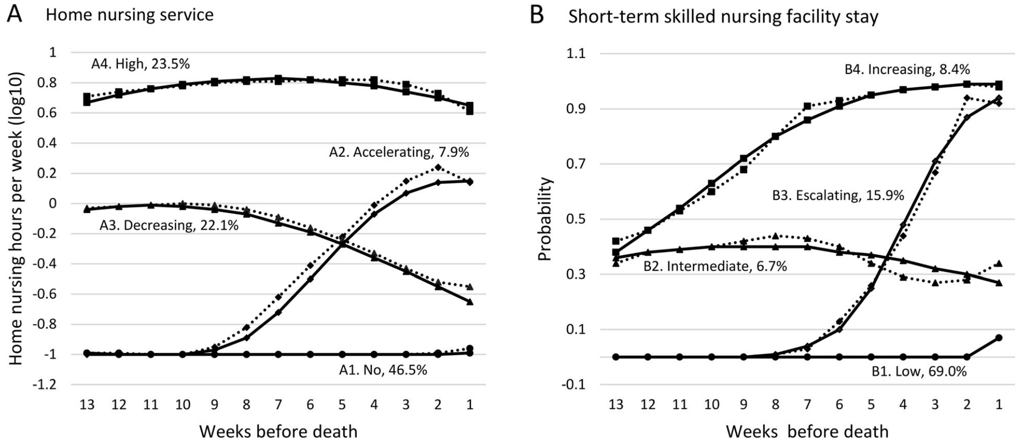

Fig. 2 Home nursing service trajectories (**a**) jointly modelled with short-term skilled nursing facility trajectories (**b**) in the last 13 weeks of life. Solid lines represent predicted trajectories, dashed lines indicate observed trajectories. Percentage of population for each trajectory are shown. Home nursing service trajectories were modeled using a censored normal distribution after log transformation. A Bernoulli distribution was used to model probability of a skilled nursing facility stay each week. In total, 97.1% persons had a probability of assigned trajectory ≥ 0.70

hrs/wk. (interquartile range (IQR) 5.8), hereafter called "accelerating home nursing".

A3. 22.1% had decreasing home nursing services starting at a median of 1.0 hrs/wk. (IQR 2.1), hereafter called "decreasing home nursing".

A4. 23.5% maintained a high level of home nursing services with a median of 6.8 hrs/wk. (IQR 9.2) 5 weeks before death, hereafter called "high home nursing".

The four trajectories for short-term SNF stays are shown in Fig. 2 (B1-B4):

B1. 69.0% had a consistently low probability of SNF, hereafter called "low SNF".

B2. 6.7% had an intermediate probability of SNF, hereafter called "intermediate SNF".

B3. 15.9% had an initial low probability of SNF escalating from 7 weeks before death, hereafter called "escalating SNF".

B4. 8.4% had a trajectory with increasing probability of SNF, hereafter called "increasing SNF".

Potentially planned home deaths

We estimated that 12,790 (24.0%) deaths were potentially planned to take place at home (Fig. 1). Receiving home nursing 14 days instead of 7 days before death, yielded marginally more (13,603; 25.5%) potentially planned home deaths, resulting in a higher proportion of SNF deaths. Actual place of death for the 12,790 potentially planned home deaths was 27.1% home, 18.0% SNF, 53.8% hospital and 1.0% other locations. In total, only 6.5% of all deaths were potentially planned to take place at home and occurred at home. This corresponds to 15.8% potentially planned home deaths in the entire deceased population in the same period, with 4.3% of all deaths being potentially planned home deaths that occurred at home.

Comparing potentially planned home deaths and nursing care trajectories

Nearly half of people with conditions that predicted a potentially planned home death had high home nursing services (11.3%) (Fig. 3). An additional 4.7% of the population had potentially planned home deaths and accelerating home nursing. Almost all patients with potentially planned home deaths had a low probability of going to a nursing home, regardless of which home nursing trajectory they followed. Somewhat unexpectedly, this included those with decreasing home nursing. For people with unplanned home deaths, 4.2 and 4.3% had no home nursing and followed the increasing or escalating SNF trajectories, respectively. In general, people with unplanned home deaths had a larger proportion of people who followed trajectories with increased probability of having a short-term SNF stay towards the end-of-life.

Associations between place of death, potentially planned home deaths and home nursing service trajectories

We found no significant association between death at home versus hospital or SNF versus hospital and

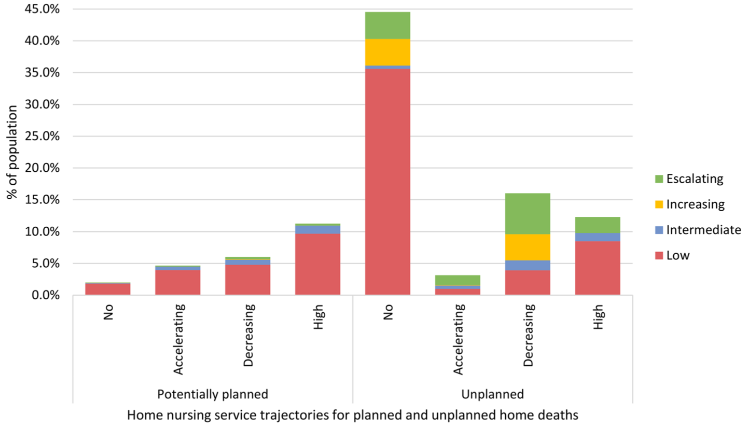

Fig. 3 Joint probability of being a member of a specific home nursing service trajectory and a specific short-term skilled nursing facility trajectory for potentially planned and unplanned home deaths. The probabilities sum up to 100%

potentially planned home deaths after adjusting for other factors (Table 2).

Only people following the high home nursing trajectory had increased likelihood of dying at home compared to hospital (aRRR 1.29, CI 1.21–1.38) (Table 2). Decreasing home nursing was associated with reduced likelihood of home death (aRRR 0.90, CI 0.83–0.97), while no significant association was found for accelerating home nursing. People following trajectories of high (aRRR 1.58, CI 1.47–1.70), decreasing (aRRR 1.43, CI 1.34–1.54) and accelerating home nursing (aRRR 1.23, CI 1.11–1.36) were all more likely to die in a SNF than hospital. Increasing SNF, escalating SNF and intermediate SNF were all associated with reduced likelihood of a home death and higher likelihood of dying in a SNF compared to hospital. In general, younger age groups were associated with increased likelihood of dying at home and less likelihood of SNF deaths compared to hospital. Those aged ≥90 years were more likely to die both at home and in SNFs than in hospitals. People living in the least central municipalities had the highest likelihood of dying both at home (aRRR 1.24, CI 1.16–1.34) and in SNFs (aRRR 1.56, CI 1.45–1.69), compared to hospitals.

Discussion

We identified four home nursing service trajectories and four short-term SNF trajectories in the last 3 months of life in this community-dwelling population. An estimated 24.0% were potentially planned home deaths, of which a third occurred at home. Half of people with potentially planned home deaths followed the high home nursing trajectory. Only high home nursing was associated with increased likelihood of dying at home. Following any trajectory with elevated probability of a SNF stay reduced the likelihood of a home death. We believe we are the first to use trajectory modeling to investigate patterns of care for home nursing simultaneously with short-term SNF stays in the last months of life and to calculate associations with place of death.

Strengths of our study are the national coverage and registry-based data. We had access to large numbers of deaths providing higher power, using state-of-the-art modelling and had an excellent fit. Universal healthcare with access to services for all inhabitants in Norway requiring such services, increases validity of our findings. Limitations include lack of information on hospital admissions, date of admission for hospital deaths, and contacts with family physicians or specialized palliative care services. As no registry-based information source was available, we estimated potentially planned home deaths. While receiving home nursing services seven or 14 days before death is a narrow definition, this was considered the latest initiation compatible with building relationships and providing palliative care at home. Almost all people with potentially planned home deaths started home nursing at an earlier time. However, we cannot rule out that some, especially younger people, may have died at home with support from family caregivers and possibly hospital-based specialized palliative care. We could not investigate this further, as information on cohabitation was only available for those who received municipal care. Additionally, we cannot exclude planned home deaths for other diagnoses than those included in our definition. The current algorithm led to 3471 (4.3% of all) home deaths being classified as potentially

Table 2 Adjusted relative risk ratios (aRRR) for dying at home, skilled-nursing facility or other location compared to hospital and their associations with potentially planned home deaths, home nursing trajectories and skilled nursing facility trajectories

	Home versus Hospital			SNF versus Hospital			Other[a] versus Hospital		
	aRRR	CI	p	aRRR	CI	p	aRRR	CI	p
Potentially planned home death (ref. unplanned)	0.94	0.89–1.00	0.066	0.96	0.90–1.03	0.264	0.28	0.23–0.34	< 0.001
Home nursing trajectory (ref. no)									
Accelerating	0.93	0.85–1.03	0.168	1.23	1.11–1.36	< 0.001	0.30	0.21–0.43	< 0.001
Decreasing	0.90	0.83–0.97	0.004	1.43	1.34–1.54	< 0.001	0.66	0.55–0.79	< 0.001
High	1.29	1.21–1.38	< 0.001	1.58	1.47–1.70	< 0.001	0.51	0.43–0.61	< 0.001
SNF trajectory (ref. low)									
Increasing	0.40	0.34–0.47	< 0.001	17.93	16.43–19.56	< 0.001	0.19	0.12–0.30	< 0.001
Intermediate	0.65	0.59–0.72	< 0.001	2.27	2.08–2.47	< 0.001	0.37	0.26–0.54	< 0.001
Escalating	0.32	0.28–0.36	< 0.001	14.14	13.21–15.14	< 0.001	0.14	0.09–0.22	< 0.001
Female (ref. male)	0.85	0.81–0.89	< 0.001	1.13	1.07–1.19	< 0.001	0.49	0.44–0.54	< 0.001
Age (years) (ref. 80–89)									
0–39	1.63	1.45–1.84	< 0.001	0.20	0.15–0.27	< 0.001	7.84	6.61–9.31	< 0.001
40–49	1.80	1.59–2.03	< 0.001	0.57	0.46–0.69	< 0.001	6.22	5.15–7.51	< 0.001
50–59	1.59	1.46–1.83	< 0.001	0.71	0.63–0.80	< 0.001	3.75	3.19–4.41	< 0.001
60–69	1.30	1.22–1.39	< 0.001	0.82	0.75–0.89	< 0.001	2.38	2.04–2.76	< 0.001
70–79	1.06	1.00–1.13	0.060	0.91	0.85–0.97	0.005	1.36	1.16–1.59	< 0.001
90+	1.20	1.11–1.30	< 0.001	1.55	1.44–1.67	< 0.001	0.66	0.49–0.87	0.003
Municipality centrality[b] (ref. central)									
Least central	1.24	1.16–1.34	< 0.001	1.56	1.45–1.69	< 0.001	1.53	1.34–1.75	< 0.001
Less central	1.06	0.97–1.16	0.205	1.12	1.02–1.24	0.023	1.28	1.09–1.51	0.003
Somewhat central	1.13	1.06–1.20	< 0.001	1.21	1.13–1.29	< 0.001	0.99	0.88–1.12	0.868

Note. Multinomial logistic regression with place of death as dependent variable. Number of observations 53,177

Abbreviations: *SNF* skilled nursing facility

[a] Other place of death includes abroad, under transportation to hospital, other specified

[b] Classification based on geographical distance to center with higher functions

planned compared with 5089 (6.3%) in our previous publication, because of a refinement of the inclusion criteria [8]. We consider the 24.0% potentially planned home deaths a valid estimate because palliative care is mostly offered to cancer patients and planned home deaths are unlikely without home nursing [17, 22].

People with potentially planned home deaths for the most part had a low probability of having a short-term SNF stay and half received high hours of home nursing. Home nursing service utilization indicates that time at home and possibly home death was prioritized. People receiving high home nursing was also the only group with significantly higher likelihood of home death. A plausible explanation is that people following this trajectory had high care needs over a longer period, received home nursing from familiar caregivers and felt secure staying at home. The evidence from previous studies are conflicting on home nursing and associations with days spent at home [23, 24], and timing of palliative care [25, 26].

Our findings imply that continuity of services is an important factor to stay longer at home and die at home. This is further supported by that we did not find any significant association between accelerating home nursing and home death, although home time seems to have been prioritized also here. Accelerating home nursing started closer to death, never reached the number of hours provided to people receiving high home nursing; and may in the end have been too little, too late to die at home. To have continuity and timely start-up of services, the patient and family's preferences of place of care and death must be known to healthcare providers. This can be achieved through advance care planning, which has been shown to both increase chances of dying at home and improve quality of care [27, 28].

Cancer patients constituted the largest group in all trajectories receiving home nursing. They also more commonly have advance care planning [27]. This may be attributed to cancer having a terminal phase that is easier to predict [29]. Two-thirds of patients receiving accelerating home nursing services died from cancer and fits well with a response to a well-defined trajectory of rapid functional decline at the end-of-life; mostly attributed to cancer patients [29]. Yet, another cohort-study found that most people did not have a distinct trajectory based on cause of death [30]. There was, however, agreement on substantial functional decline in the last months of life regardless of diagnosis [29, 30]. So if most people with a non-sudden death have rapid functional decline approaching death [29, 30], our findings indicate many missed opportunities to identify and provide palliative homecare to enable people to stay longer at home; especially non-cancer patients.

Home death is not feasible for all dying persons, and for these, transitions to SNF or hospital may be appropriate. To illustrate, people who received high home nursing hours and had escalating probability of a SNF stay most likely represent high care needs over time where declining function, lack of symptom control, high caregiver burden or living alone may have led to a necessary transition. On the other hand, 22% of decedents followed a trajectory of decreasing home nursing services. Of these, 50% were already in a SNF before the last week of life and hence not considered potentially planned home deaths. Another 40% had a low joint probability of a SNF stay. More intensive home nursing services may represent an alternative to SNF or hospital admission at the end-of-life. A majority never received home nursing services and had low probability of SNF stays. Some represent sudden or unexpected deaths, and some younger patients were probably cared for by family caregivers. Still, it is likely that a significantly larger proportion could have benefited from receiving palliative home nursing at an earlier stage [31].

With increasing demand for palliative care regardless of diagnosis, specialized palliative care cannot alone meet the needs of patients and families [32]. A recent Swedish study found that a majority of quality indicators for end-of-life care in the last week of life were better for patients dying in community-based settings in regions with less developed palliative care compared to fully developed palliative care [33]. General palliative care should be provided by all relevant healthcare personnel, while specialist palliative care should manage more complex cases [32]. Together with an involved family physician, home nursing services could be a viable alternative for providing general palliative care to people according to their wishes, regardless of diagnosis [34]. For this to work, we must also address inadequate policies and guidelines, gaps in continuity and coordination of care and increase the knowledge and skills in palliative end-of-life care for all health personnel [34–36].

Conclusions

Our estimates show a low number of potentially planned home deaths in Norway. Trajectories of home nursing hours and probability of SNF stays indicated possible effective palliative home nursing for some, but also missed opportunities of staying at home longer at the end-of-life. Continuity of care seems to be an important factor in providing home nursing and dying at home. Transitions from home need further research to ascertain if current policies maximize time spent at home and increase the likelihood of home deaths. Future studies should also investigate how family physicians follow up patients at the end-of-life and whether they can contribute to an increased number of planned home deaths.

Abbreviations

aRRR: Adjusted relative risk ratio; Hrs/wk.: Hours per week; IPLOS: National register for statistics on municipal healthcare services; IQR: Interquartile range; NCoDR: Norwegian Cause of Death Registry; PPA: Average posterior probability of assignment; SNF: Skilled nursing facility

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Author's contributions

CK contributed to the study design, analysis, interpretation, drafting and revision of the manuscript. SH contributed to the study design, interpretation, drafting and revision of the manuscript. LH contributed to analysis, interpretation and revision of the manuscript. HA contributed to analysis, interpretation and revision of the manuscript. EF contributed to the study concept and revised the manuscript. BH contributed to the study concept and revised the manuscript. All authors read and approved the final version of the manuscript.

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Availability of data and materials

The data that support the findings of this study are available from NCoDR and IPLOS but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of NCoDR and IPLOS.

Ethics approval and consent to participate

The study was approved by the Regional Committee for Medical and Health Research Ethics North (2014/2308) and the Norwegian Data Protection Authority (15/00450–2/CGN, 17/00341–3/SBO). Approvals to access, linkage and use of registry data was given by the responsible authorities: the Norwegian Institute of Public Health (NCoDR) and the Norwegian Directorate of Health (IPLOS).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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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 dieds 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	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
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)

[a] Municipality centrality missing for 448 individuals.

[b] Marital 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

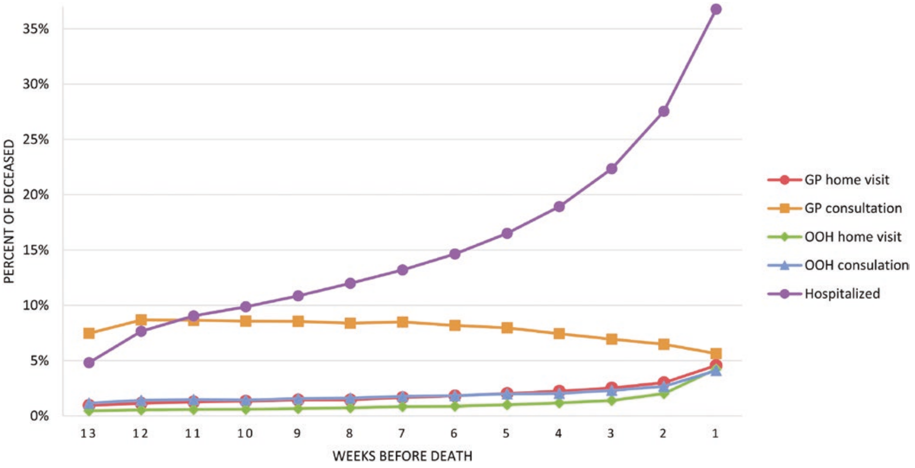

Figure 1. Percentage of all deceased with one or more of contact types: GP home visit, GP office consultation, OOH home visit, OOH consultations and/or hospitalization each week in the last 13 weeks of life.

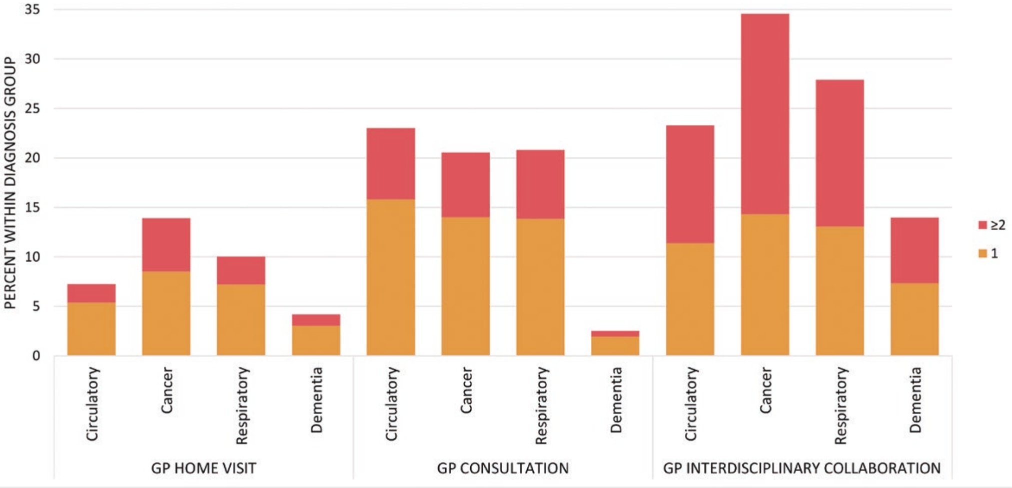

Figure 2. Percent of patients receiving GP home visits, office consultations and GP interdisciplinary collaboration in the last 4 weeks of life for the most common causes of death. Columns represent percent of patients within each of the four most common cause of death diagnosis groups.

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 sociodemographics; 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

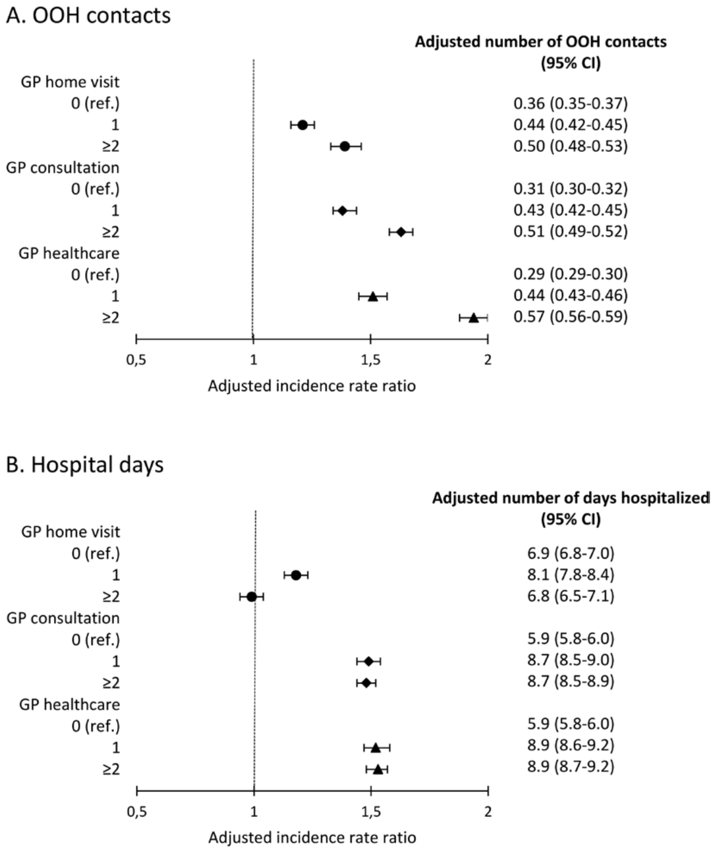

Figure 3. Associations between GP home visits, office consultations and GP interdisciplinary collaboration (GP collaboration; including telephone and interdisciplinary meetings) and (A) total number of OOH contacts and (B) total number of days hospitalized. Adjusted analyses with IRR and 95% CI error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