Geographic Variations in Home-based Care and Hospital Use in End-of-Life Cancer Care in Norway: a Registry-based Study

Candidate: Nora Mork Østbø

Master's of Philosophy: Health Economics, Policy and Management
Spring 2023
Faculty of Medicine
Institute of Health and Society
Department of Health Management and Health Economics
University of Oslo
Supervisor: Gudrun W. Bjørnelv
Co-supervisor: Eline Aas

Acknowledgements

I would like to thank my supervisors, Gudrun Waaler Bjørnelv and Eline Aas, for their thorough guidance in every step of the thesis work. It has been a pleasure and an inspiration to work with you on the end-of-life project, in all capacities. Thank you for sharing your knowledge and expertise with me, and for giving me the opportunity to learn from you.

I want to thank the administration and lecturers at the Department of Health Management and Health Economcis at the University of Oslo. A huge thank you to Mari Mjøen for her guidance throughout the two years. I would also like to thank my classmates for the many hours spent on the second floor of Harald Scheldrups Hus while writing our theses, for the friendships, and their support.

Table of Contents

Appendices

List of abbreviations

EoLC = End-of-life care

NPR = Registry, Norwegian Patient Registry (NPR)

NRPC = the Norwegian Registry for Primary Healthcare

ICD 10 = International Classification of Diseases version 10

CCI = Charlson Comorbidity Index

AIC = Akaike Information Criterion

BIC = Bayesian Information Criterion

AME = Average Marginal Effects

Km = Kilometers

REK = Regional Ethics Committee

SD = Standard deviation

NOK = Norwegian Kroner

OLS = Ordinary least squares regression

List of figures and tables

ABSTRACT

INTRO: Cancer is the leading cause of death in Norway, accounting for a quarter of all deaths. Quality end-of-life care is an important aspect of treatment, and Norway's palliative care policy highlights the importance of providing care in the individual's preferred location, which is often at home. However, many patients live in rural municipalities with long distances to access healthcare services, which may be a barrier to at-home care. Main objectives of this study were to identify factors associated with time spent at home and in the hospital in the last six months of life, and explore the association between geographic factors and end-of-life care location.

METHODS: This study utilized data from four national registries, including the Norwegian Causes of Death Registry, Norwegian Patient Registry (NPR), the Norwegian Registry for Primary Healthcare (NRPC), and Statistics Norway. The study population consisted of individuals who died of cancer between 2019 and 2021, identified from the Causes of Death Registry. Variables associated with days at home and in hospital in the last six months of life were assessed using a two-part model using logistic regression and OLS. Sociodemographic/medical variables included in regression analyses were sex, age, marital status, education level, income, year of death and comorbidity. Geographic factors were municipality population size, county of residence, and distance to the nearest hospital. Stratified analyses were conducted according to sex.

RESULTS: From 2019 – 2021, 32,710 individuals died from cancer and were included in this study. The majority were aged 71-80 (55%), male (53%) married, had secondary school education (45%), and made between 200 – 400 000 NOK/year. Most (72%) had mild or moderate comorbidities (<5 CCI), and lived the 20% largest municipalities (68%). The average distance to the nearest hospital was 31.3 kilometers. Significant positive associations were identified between days at home and male sex, lower age, being married or having a partner, higher education and income. Larger distances to hospital were associated with fewer days at home and hospital, and more time in long-term care. Agder and Viken county had the highest number of days at home, and Oslo county had the highest number of days in hospital.

DISCUSSION: Inaccessibility due to geographic factors is a central issue facing the healthcare sector, and policies regarding EoL care for individuals with cancer needs to consider these inequalities. Our findings shed light on the barriers faced by individuals residing in rural or remote areas in accessing healthcare services. Individuals living in urban areas may have better access to short-term facilities that can periodically provide relief and support for the sick individual and their family. These findings highlight the influence of geographic factors on care patterns at the end of life for cancer individuals in Norway.

CONCLUSION: Easier access to healthcare services in terms of place of residence, including living close to a hospital and in an urban location, are independent predictors of more time spent at home at EoL and in hospital. Understanding these patterns can help identify areas for improvement in EoL healthcare services

INTRODUCTION

Cancer is the leading cause of mortality in Norway, accounting for approximately 25% of all deaths (1). Quality end-of-life care (EoLC) is a critical component of cancer care, and maximizing the time spent at home in the last six months of life is a key individual-driven quality indicator (2, 3). The American National Cancer Institute defines EoLC as “care given to people who are near end of life and have stopped treatment to cure or control their disease” (4). EoLC involves physical, emotional and spiritual support, often in the context of supportive or palliative care. This may take place in a variety of settings, including long-term and short-term care institutions, hospice, hospitals, and in the dying individual’s own home. In Norway, the government's palliative care policy emphasizes the importance of providing care in the individual's preferred location, which is often at home (5, 6). Individuals who receive at-home care may experience better quality of life, a greater sense of control, better global health, and lower levels of depression (7, 8). Around half of a person’s lifetime hospital admissions and bed occupancy occurs in the last year of life and more specifically in the last six months, therefore enabling individuals to live and receive EoLC at home may also be a cost-saving alternative (9, 10, 11). However, the reality is that many individuals die in institutions, such as hospitals or long-term care homes (12). The reasons for this may be complex and multifactorial, and may, among other factors, include individual characteristics and preferences, and access to necessary care and resources.

Much of previous research on the geographic implications in EoL care in cancer has focused on factors associated with place of death, rather than where the individual lives in the time leading up to death. Although time at home and home death are certainly related, they are not synonymous. Place of death will vary depending on the individual’s personal situation and preferences (13, 14). Most individuals, however, wish to partake in normal life as much as possible in the time leading up to death (2, 13, 15). Many may therefore wish to live at home to maintain their social contacts and routines at home in their last few months of life. However, few studies have assessed factors associated with spending more or less time at home in this patient population in a Norwegian conext. A recent study from Norway found that the time spent at home in the last six months of life for cancer individuals dying between 2009 and 2013 was strongly associated with lower age and access to informal care at home (16). Older individuals may be more likely to have complications related to their cancer or treatment and may also have care needs that exceed what home-based caregivers can provide (17). Older individuals may also have spouses that are deceased or older and frail, and unable to provide practical support. Studies have linked time at home with marital status and lower age, likely due to the presence of a familial support system (16, 17). Education and income have also been found to be positively associated with lower risk of death from cancer in Norway, also when adjusting for place of residence (18). Higher income and education level have in a Nordic context been shown to be positively associated with cancer-related outcomes, including early diagnosis and survival (19).

Individuals with higher socioeconomic status (education and income) may have a better care trajectoy due to higher health literacy, and better access to health information and resources (20). Research from Norway in a cancer context has indicated that income and education are positively linked to hospital care in last six months of life, and associated with less time spent in municipal institutions and more time at home (16). However, no previous studies have investigated the role of geographic place of residence in utilization of healthcare at EoL in a Norwegian cancer context.

Where in the country a person lives may play a vital role in determining the care that is available to the individual. One previous study showed that cancer prognosis varies by geographic region in Norway, despite efforts by the government and Directorate of Health to put in place standardized care pathways for cancer to minimize inequalities in care (18, 21). Potentially important geographic factors may include urban/rural residence, overarching regional inequalities, and travel time to a hospital, emergency services, or other relevant care institutions. Individuals living in rural, sparsely populated areas may have limited access to healthcare services due to scarcity of healthcare facilities and providers, and limited access to specialists (18). Home-based nursing services may not be available, or may not be able to provide sufficient home-based care at the level that is often required at EoL due to limited personnel or other resource constraints. Individuals may face transportation barriers and need to travel longer distances to access specialized or urgent healthcare services (19). Distance to hospital may therefore be an important factor in the feasibility of a terminally ill individual living at home. Longer travel time to the nearest hospital may be a barrier to access emergency care, and individuals may choose to live in care facilities to ensure access to prompt care when needed (18). In addition, there may exist regional variation and inequalities in healthcare services that are not explained by aforementioned factors.

Understanding the factors that influence the location of care at the end of life can inform the development of interventions to improve access to palliative care services, reduce institutional deaths, and promote individual-centered care. The primary objectives of this study were to identify factors associated with more or less time at home and in hospital in the last six months of life, using updated data from 2017 - 2021, and estimate the association between geographic factors and time at home and in hospital at end of life for persons with cancer. Secondary objectives were to investigate potential differences in days at home and in hospital separately for men and women.

METHODS

Data was linked from four national registries, including the Norwegian Causes of Death Registry, Norwegian Patient Registry (NPR), the Norwegian Registry for Primary Healthcare (NRPC) and Statistics Norway (22, 23, 24, 25). The study population included all individuals who died of cancer (ICD-10 codes C00 – C97) in Norway between 2019 and 2021, identified from the Norwegian

Causes of Death Registry (25). The registry captures information on both immediate and underlying cause(s) of death, as reported by the physician who completes the death certificate. If the immediate cause of death was non-cancer-related, but the underlying cause of death was registered as cancer, the individual was included in the study. All data were linked at individual level using a unique identification number. Below, we describe the information derived from each registry and statistical methods used.

Patient registries

The study population was linked to the NPR, which includes detailed information about all public hospital admissions, including primary and secondary diagnoses pertaining to the patient, which was used to describe primary cancer diagnosis (ICD-10). Individual-level data on all decedents, including sex, age at death, marital status, highest level of completed education, yearly personal income in NOK, and municipality and county of residence, was linked from Statistics Norway. Information on all healthcare service use was extracted from the NPR and the NRPC. The NPR was established in 2008, and the NRPC was later established in 2017. Reporting to these registries is mandatory, and the Norwegian Directorate of Health oversees both registries. The NPR contains information on individuals who have received in-patient specialized healthcare at a hospital, out-patient clinic or from contract specialists (23). Information on consults and treatments is registered by hospitals according to diagnosis-related group (DRG) codes to enable reimbursement by the state. The registry was used to derive information on all treatments provided in a hospital setting in the 18 months prior to death. The NRPC was used to gather information on the length of stay in municipal care institutions, including short-term and long-term care facilities. The registry contains information regarding start- and end-dates of municipal care institution stays, but does not contain information on stays that began prior to the establishment of the registry database. The NRPC was established in 2017 and therefore does not contain information about long-term institution stays that began prior to that year. This may result in a falsely deflated average for days at home for some time post the beginning of the registry. After inspecting the data on average days spent in a long-term care facility per year, this average stabilized from the year 2019. Therefore, only decedents who died between 2019 and 2021 were included in this study.

Dependent variables – days at home and days hospitalized

To estimate the total number of days each individual spent at home during the last six months before death, the number of days the individual spent in hospital, in long-term institutions, and in short-term institutions was subtracted from the total number of days in the 6-month period (181 days). Long-term care facilities are municipally-funded care homes or other adapted housing specifically tailored for individuals with extensive nursing and care needs. Short-term care facilities are also municipally-funded and are suited for individuals with care needs who normally live at home but require additional care for a restricted period, for example for treatment, observation, or relief for the family. For hospital stays, only in-patient admissions with at least one night in the hospital were included in days away from home.

Independent variables

Age at death and biological sex were included as independent demographic variables. Partner status was used as a proxy for having access to informal care at home. To assess the impact of socioeconomic status, years of completed education and yearly personal income were included. The Charlson Comorbidity Index (CCI) is an assessment tool designed specifically to predict long-term mortality when the person's concurrent conditions are known. A score of zero means that no comorbidities were found; the higher the score, the higher the predicted mortality rate is. For each individual, comorbid conditions were derived from hospital records (ICD-10 codes) in NPR, including both primary and secondary diagnoses, from 18 to 7 months before death (26)

We assessed geographic factors through three different variables: population size of the municipality where the decedent resided, county of residence, and an estimate for the distance to the nearest hospital. Norway has had several regional reforms and mergers of municipalities and counties since data collection began in 2017. Municipality and county of residence are provided according to most recent updates to the geographic structure as of May 2023. Population size for each municipality is given according to number of inhabitants in January 2020. Distance to the nearest hospital was estimated based on the coordinates of the geographic center of the municipality and the coordinates of the nearest public hospital. To assess a potential non-linear relationship between distance to hospital and the outcome variables, a squared term for distance to hospital in km was included in regression analyses. Coordinates were provided by Kartverket (Hønefoss, Norway) (27). Information on distance from nearest hospital was available for 317 (89%) of 356 municipalities.

Statistics

Regression model selection was performed by assessing the characteristics of the outcome variable and choosing the best model from a set of appropriate models. As the outcome variables (time at home and in hospital) were provided in units of days in the data, this is considered count data. Overdispersion of the data was present, and the data was negatively skewed, with a high number of zero values. Negative binomial regression and a two-part model with logistic regression in the first part to assess the likelihood of living at home for >0 days, and ordinary least squares regression (OLS) in the second part, were compared. The two-part model was ultimately selected using the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC) (28). Results from the regression models are presented as the average marginal effects in their original units.

Descriptive statistics were used to describe sociodemographic and disease characteristics for the entire sample, and when dividing the sample according to municipality population size. Age and sex were presented descriptively as continuous and categorical variables, respectively, and sorted into categories in the regression model. Age was categorized as below 50 years, 50–59, 60–69, 70–79, 80–89, or > 90. Decedents who were currently married or had a registered partner at the time of death were compared to those who had previously been married or had a registered partner (i.e. divorced, separated, or widowed), or had never been married or had a registered partner. Education level was grouped into levels of completed education, including primary school (10 years), secondary school (13 years), and higher education (at least 14 years). Yearly personal income in NOK was divided into categories (<200 000; 200 – 400 000; 400 001 – 600 000; 600 001 – 800 000; >800 001). The CCI was calculated for each individual, and the score was grouped into mild/moderate (0-4) and severe (>5). Individuals that did not have any hospital contacts 18 to 7 months prior to their death, were assumed to have mild comorbidities. The most common cancer types was summarized in descriptive statistics but excluded from the regression model as previous research has shown cancer type to not be associated with EoL healthcare use (16).

To estimate the combined effect of sociodemographic variables on days at home and in hospital without geographic variables, separate regression models were conducted using only the sociodemographic variables. Results are presenting with the estimate for days at home and in hospital for the reference category, as well as the marginal differences. Analyses were conducted for all geographic variables (county of residence, municipality of residence, and distance to nearest hospital) separately (herein referred to as Model 1-3), in pairwise combinations (herein referred to as Model 4-6), and all combined (herein referred to as Model 7). When analyzing geographic location, all models were fully adjusted for sociodemographic and medical variables. Each municipality was sorted into quintiles according to population size (1 = <1858; 2 = 1858 – 3427; 3 = 3428 – 6810; 4 = 6811 – 17 316; 5 = >17 316). All 11 counties (Agder, Innlandet, Møre og Romsdal, Nordland, Oslo, Rogaland, Troms og Finnmark, Trøndelag, Vestfold og Telemark, Vestland, Viken) were included. Distance in kilometers (km) to the nearest hospital from the geographic center of the municipality was included as a continuous variable. Stratified analyses were conducted according to sex, in accordance with best practice guidelines by the Norwegian National Reseach Ethics Committees, and recommendations by the International Committee of Medical Journal Editors (29, 30).

This study was approved by the regional ethics committee (REK). Privacy considerations were evaluated using a DPIA, and approved. Permissions were obtained from all registry administrations.

RESULTS

Individual characteristics

Between 2018 and 2021, 32 710 people died of cancer in Norway, of which 6 547 (20%) had an underlying cause of death of malignant neoplasm of the bronchus and lung (ICD-10 C34), 3 553 (11%) of malignant neoplasm of the colon (ICD-10 C18), 2 813 (9%) of prostate (ICD-10 C61), and 1 803 (6%) of breast cancer (ICD-10 C50). Other cancer types made up the remaining 54% of deaths. Almost one-third were between the ages 71 to 80 at death, and 1 203 (4%) were under the age of 50. About half (53%) were male and were married or had a registered partner (49%). The majority had an income between 200 – 400 000 NOK (59%), and most had completed either primary school education (33%) or secondary school education (45%). Most (n = 23 541, 72%) had a mild/moderate comorbidity index. Most (n = 22 280, 68%) lived in the 20% largest municipalities with more than 17 317 inhabitants, while only 914 (3%) lived in the 20% smallest municipalities with less than 1 857 inhabitants. See table 1 for all details.

Descriptive statistics

The average distance to the nearest hospital, irrespective of place of residence, was 31.3 km (SD = 37). The estimated distance to the nearest hospital exhibited substantial variability across different counties (Figure 1). The distance was greatest for northern regions, including Troms og Finnmark (mean 81.7, SD = 86.6) and Nordland (mean = 55.6, SD = 47.6). Oslo had the shortest estimated distance to a hospital at 7.4 km. There was a linear relationship between distance to the nearest hospital and the population size of the municipalities (Figure 2). This relationship revealed a consistent trend of increased distance to hospitals as the number of inhabitants in a municipality decreased. The 20% smallest municipalities displayed the longest travel distances, with an average of 99.3 (SD = 71.1) km to the nearest hospital, compared to 21.3 (SD = 25.4) km for the 20% largest municipalities. Moreover, municipalities falling within the second, third, and fourth quintiles had average distances of 84.9 km (SD = 55.8), 63.6 km (SD = 42.7), and 37.0 km (SD = 27.1) to the nearest hospital, respectively.

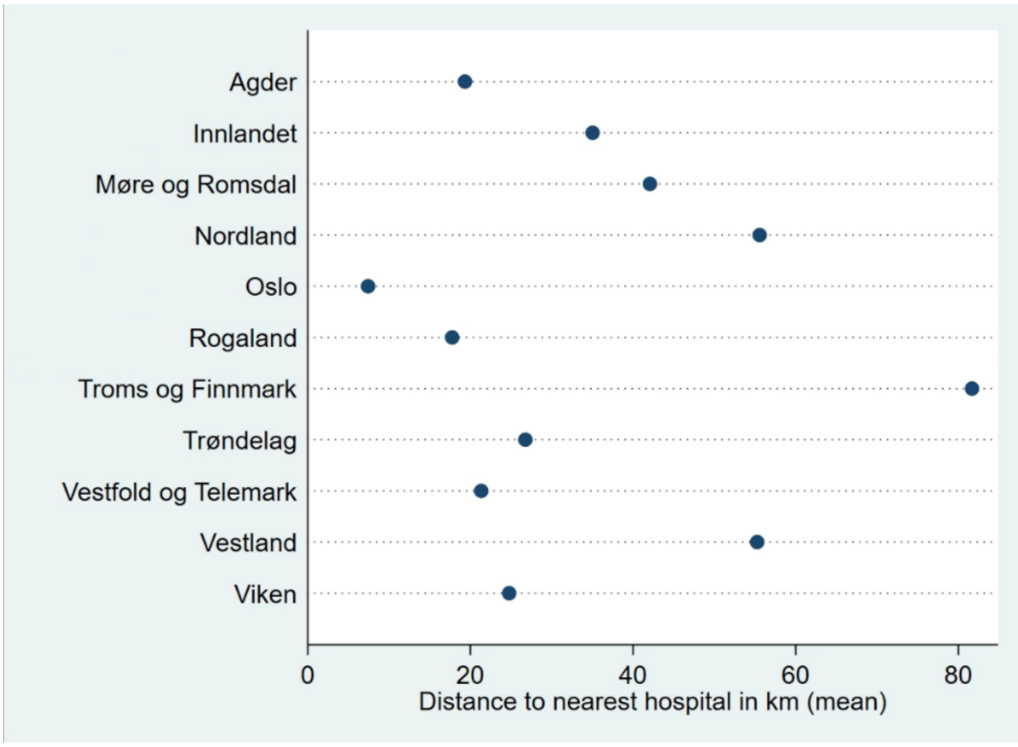

Figure 1. Average distance to hospital across counties.

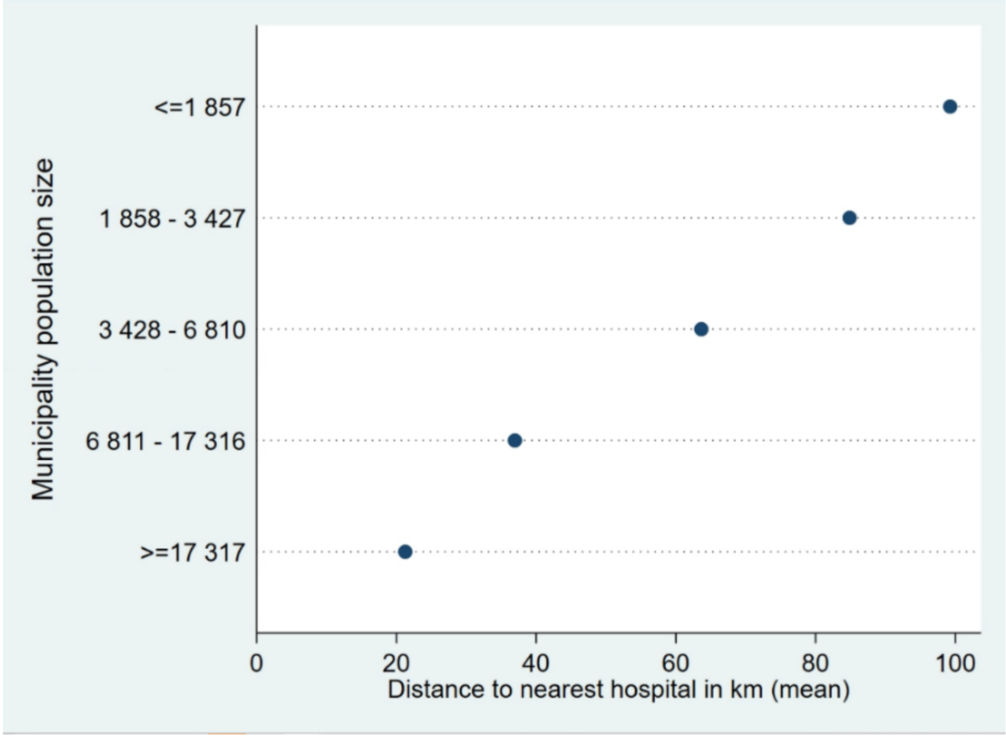

Figure 2. Average distance to hospital according to municipality population size.

Care Patterns at the End of Life

Decedents spent an average of 123.5 days (SD = 56.0) at home, 20.4 days (SD = 18.7) in the hospital, 13.8 days (SD = 23.3) in short-term care, and 25.0 days (SD = 59.4) in long-term care in the last six months before death. The duration of time spent at home showed a positive association with municipality size. Among individuals residing in the 20% smallest municipalities (n = 914), the average number of days spent at home in the last six months of life was 117.3 (SD = 61), compared to 124.5 (SD = 54.7) for those living in the 20% largest municipalities (n = 22 280). Notably, those residing in municipalities classified within the second to fourth quintiles in terms of population size spent an average of 119.2 (SD = 60.1), 121.5 (SD = 59.5), and 122.5 (SD = 57.2) days at home, respectively. In contrast, the duration of time spent in long-term care exhibited a negative association with municipality size. Decedents in the first quintile of municipality size spent an average of 32.3 days (SD = 65.7) in long-term care, compared to 23.3 days (SD = 57.6) for those in the fifth quintile. Decedents in the largest quintile spent two more days in hospital compared to decedents in the two smallest quintiles. Number of days in short-term care did not show marked differences according to municipality size. See Table 1.

Table 1. Descriptive statistics of the full sample and divided into municipality population size.

	Full sample	**<=1 857 inhabitants**	**1 858 – 3 427 inhabitants**	**3 428 – 6 810 inhabitants**	**6 811 – 17 316 inhabitants**	**>17 317 inhabitants**
	N = 32 710	**N = 914**	**N = 1 580**	**N = 2 833**	**N = 5 103**	**N = 22 280**
Age in years, mean (std)	75.1 (12.6)	76.1 (11.4)	76.1 (11.7)	75.6 (12.0)	75.6 (12.3)	75.0 (12.8)
Age in years categories, n (%)						
=<50	1 203 (3.7)	20 (2.2)	42 (2.7)	90 (3.2)	171 (3.4)	880 (4.0)
51 – 60	2 587 (7.9)	54 (5.9)	97 (6.1)	203 (7.2)	381 (7.5)	1 852 (8.3)
61 - 70	6 194 (18.9)	184 (20.1)	283 (17.9)	552 (19.5)	948 (18.6)	4 227 (19.0)
71 - 80	10 869 (33.2)	311 (34.1)	551 (34.9)	950 (33.5)	1 725 (33.7)	7 332 (32.9)
80 – 90	8 845 (27.1)	257 (28.1)	482 (30.5)	766 (27.0)	1 418 (27.8)	5 922 (26.6)
>90	3 012 (9.2)	88 (9.6)	125 (7.9)	272 (9.6)	460 (9.0)	2 067 (9.2)
Male sex, n (%)	17 427 (53.3)	538 (58.9)	838 (52.4)	1 567 (55.3)	2 833 (55.5)	11 661 (52.3)
Education[a], n (%)						
Primary school	10 725 (33.1)	369 (41.4)	631 (39.9)	1 133 (40.0)	1 922 (37.7)	6 670 (29.9)
Secondary school	14 441 (44.6)	419 (45.8)	693 (43.9)	1 237 (43.7)	2 339 (45.8)	9 753 (43.8)
Higher education	6 246 (19.3)	103 (11.3)	193 (12.2)	374 (13.2)	688 (13.5)	4 888 (21.9)
Other*	951 (3.0)	23 (2.5)	63 (4.0)	89 (3.1)	154 (3.0)	969 (4.3)
Married or registered partner[b], n (%)	15 953 (48.9)	465 (50.9)	749 (47.4)	1 365 (48.2)	2 574 (50.4)	10 800 (48.7)
Income, NOK, n (%)						
<200 000	3 033 (9.3)	109 (11.8)	210 (13.3)	293 (10.3)	495 (9.7)	1 926 (8.6)
200 000 – 400 000	19 405 (59.3)	593 (64.9)	999 (63.2)	1 841 (65.0)	3 289 (64.5)	12 683 (56.9)
400 001 – 600 000	6 806 (21.1)	158 (17.3)	256 (16.2)	508 (17.9)	912 (17.9)	5 062 (22.7)
600 001 – 800 000	1 875 (5.7)	27 (3.0)	69 (4.4)	116 (4.1)	241 (4.6)	1 422 (6.4)
> 800 000	1 501 (4.6)	27 (3.0)	46 (2.9)	75 (2.7)	166 (3.3)	1 187 (5.4)
Mild/moderate *CCI*, n (%)	23 541 (72.0)	661 (72.3)	1 150 (72.8)	2 077 (73.3)	3 630 (71.1)	16 023 (71.9)
Year of death n (%)						
2019	10.878 (33.3)	322 (35.2)	518 (32.8)	941 (33.2)	1 691 (33.1)	7 406 (33.2)
2020	10.877 (33.3)	303 (33.2)	532 (33.7)	920 (32.5)	1 676 (32.9)	7 446 (33.4)
2021	10.955 (33.4)	289 (31.6)	530 (33.5)	972 (34.3)	1 736 (34.0)	7 428 (33.4)
Cancer type (categories), n (%)						
Bronchus and lung	6 547 (20.0)	195 (21.3)	344 (21.8)	628 (22.3)	1 065 (20.9)	4 315 (19.4)
Colon	3 553 (10.8)	95 (10.5)	167 (10.6)	318 (11.3)	528 (10.4)	2 445 (11.0)
Prostate	2 813 (8.6)	97 (10.6)	125 (7.8)	269 (9.3)	454 (8.9)	1 877 (8.4)
Pancreas	2 408 (7.4)	65 (7.1)	117 (7.4)	181 (6.4)	366 (7.2)	1 679 (7.5)
Breast	1 803 (5.5)	42 (4.6)	75 (4.8)	140 (4.9)	246 (4.7)	1 300 (5.8)

Other	15 586 (47.7)	420 (45.9)	752 (47.6)	1 297 (45.8)	2 444 (47.9)	10 664 (47.9)
Care in last 6 months of life						
Days at home, mean (std)	123.5 (56.0)	117.3 (61.5)	119.2 (60.1)	121.5 (59.5)	122.5 (57.2)	124.5 (54.7)
Days in hospital, mean (std)	20.4 (18.7)	18.9 (18.5)	19.0 (18.6)	18.8 (17.9)	20.0 (18.8)	20.8 (18.8)
Days in short term care, mean (std)	13.8 (23.3)	14.3 (25.1)	12.5 (24.2)	13.4 (24.0)	14.0 (23.9)	13.8 (22.9)
Days in long term care, mean (std)	25.0 (59.4)	32.3 (65.7)	30.8 (64.8)	29.5 (63.9)	26.5 (60.9)	23.3 (57.6)
Distance to nearest hospital in km[c], mean (std)	31.3 (36.6)	99.3 (71.1)	84.9 (55.8)	63.7 (42.7)	37.0 (27.1)	21.3 (25.4)
County						
Agder	1 993 (6.1)	73 (8.0)	35 (2.2)	261 (9.2)	347 (6.8)	1 277 (5.8)
Innlandet	2 872 (8.8)	72 (8.0)	234 (14.8)	733 (25.8)	504 (9.9)	1 329 (6.0)
Møre og Romsdal	1 854 (5.7)	-	126 (8.0)	254 (9.0)	625 (12.3)	849 (3.8)
Nordland	1 718 (5.3)	163 (17.8)	339 (21.5)	201 (7.1)	522 (10.2)	493 (2.2)
Oslo	2 983 (9.1)	-	-	-	-	2 983 (13.4)
Rogaland	2 583 (7.9)	8 (0.9)	72 (4.6)	73 (2.6)	347 (7.3)	2 056 (9.2)
Troms og Finnmark	1 603 (4.9)	137 (15.0)	243 (15.4)	323 (11.4)	232 (4.6)	668 (3.0)
Trøndelag	2 811 (8.6)	309 (33.8)	129 (8.1)	212 (7.5)	742 (14.5)	1 419 (6.4)
Vestfold og Telemark	2 983 (9.1)	46 (5.0)	74 (4.7)	165 (5.8)	367 (7.2)	2 331 (10.5)
Vestland	3 801 (11.7)	74 (8.1)	231 (14.6)	325 (11.5)	785 (15.4)	2 386 (10.8)
Viken	7 426 (22.8)	32 (3.4)	97 (6.1)	286 (10.1)	605 (11.8)	6 406 (28.9)

Due to missing data: [a]N=31 41; [b]N = 32 627; [c]N=29 690.

*‘Other’ category includes trade school and no registered education.

CCI = Charlson Comorbidity Index

Regression analyses

Sociodemographic factors: Days at home

Regression results for days at home and in hospital using sociodemographic variables are provided in Table 2. Male decedents spent on average 124.4 days (95% CI 123.5 – 125.2) at home, which was 2.2 more days (95% CI 0.9 – 2.2, p < 0.01) compared to female decedents. The analysis also revealed a significant association between age and the number of days spent at home. Individuals under 50 years old spent on average 135.8 days at home. Compared to this, individuals aged 71 - 80 spent 6 fewer days at home (95% CI -8.8 - -3.1, p < 0.01), and those aged 81 - 90 spent 19.8 fewer days at home (95% CI -22.8 - -16.9, p < 0.01). Most notably, individuals over 90 years of age spent 41.1 fewer days at home (95% CI -44.7 – -37.5, p < 0.01) compared to those aged under 50. Decedents who were married or had a registered partner spent, on average, 133.9 days at home (95% CI 133.1 – 134.7), which was 25.6 more days (95% CI 23.2 – 28.0, p < 0.01) compared to those who had never been married or registered with a partner, and 18.2 more days (95% CI 16.8 – 19.5, p < 0.01) compared to individuals who had previously been married or had a registered partner.

Years of completed education was positively associated with time at home; individuals with primary school education spent 122.6 days at home (95% CI 121.6 – 123.6), while in comparison individuals with secondary school education spent 1.2 more days at home (95% CI -0.2 – 2.5, p>0.1) and those with higher education spent 1.9 more days at home (95% CI -0.1 – 3.8, p>0.1). Yearly personal income was significantly associated with more days at home. The majority of individuals (59%) were in the income bracket 200 – 400 000 NOK/year, and spent 121.1 days at home (95% CI 120.3 – 121.9). At incomes 400 001 – 600 000 NOK/year, decedents spent 7.1 more days (95% CI 5.5 – 8.7, p<0.01) at home compared to those who made <400 000 NOK. At incomes >600 000 NOK/year, this difference increased to 14.1 more days at home (95% CI 11.5 – 16.6, p>0.01). Individuals with mild/moderate CCI spent 122.7 days at home (95% CI 122.1 – 123.4), and more severe comorbidities was associated with 3.1 more days at home (95% CI 1.8 – 4.4, p < 0.01). Days at home also varied significantly depending on year of death. Individuals who died in 2019 spent 121.8 days at home (95% CI 120.8 – 122.8) and, those who died in 2020 and 2021 spent 2.1 (95% 91 0.7 – 3.5, p<0.01) and 2.4 (95% CI 1.0 – 3.8, p<0.01) more days at home, respectively.

Table 2. Association between sociodemographic factors and days spent at home and in hospital in the last 6 months of life.

	Days at home				Days in hospital			
	Beta/days	**Lower 95% CI**	**Upper 95% CI**	**p-value**	**Beta/days**	**Lower 95% CI**	**Upper 95% CI**	**p-value**
Sex								
Male (ref)	124,4	123,5	125,2		20,2	20,0	20,5	
Female	-2,2	-3,5	-0,9	***	-0,1	-0,5	0,3	
Age								
<50 (ref)	135,8	133,1	138,4		32,5	31,4	33,7	
51-60	1,1	-2,0	4,2		-4,2	-5,5	-2,9	***
61-70	-1,4	-4,2	1,5		-6,9	-8,1	-5,7	***
71-80	-5,9	-8,8	-3,1	***	-11,0	-12,2	-9,8	***
81-90	-19,8	-22,8	-16,9	***	-17,7	-18,9	-16,5	***
>90	-41,1	-44,7	-37,5	***	-23,4	-24,7	-22,1	***
Marital status								
Married or registered partner (ref)	133,9	133,1	134,7		20,9	20,7	21,2	
Previously married or registered partner	-18,2	-19,5	-16,8	***	-1,4	-1,9	-1,0	***
Never married	-25,6	-28,0	-23,2	***	-1,6	-2,3	-1,0	***
Years of completed education								
10 years (primary school) (ref)	122,6	121,6	123,6		19,9	19,5	20,2	
13 years (secondary school)	1,2	-0,2	2,5	*	0,4	-0,1	0,8	
>13 years (higher education)	1,9	-0,1	3,8	*	0,8	0,2	1,5	***
Yearly personal income (NOK)								
Under 200000	0,4	-2,0	2,6		-0,9	-1,6	-0,2	**
200-400 000 (ref)	121,1	120,3	121,9		19,8	19,5	20,0	
400 - 600 000	7,1	5,5	8,7	***	1,3	0,8	1,8	***
600 - 800 000	14,1	11,5	16,6	***	1,6	0,7	2,5	***
>800 000	14,1	11,1	17,1	***	2,9	1,8	3,9	***
CCI								
Mild/moderate (ref)	122,7	122,1	123,4		20,5	20,2	20,7	
Severe	3,1	1,8	4,4	***	-0,9	-1,4	-0,5	***
Year of death								
2019 (ref)	121,8	120,8	122,8		21,2	20,8	21,5	
2020	2,1	0,7	3,5	***	-1,7	-2,2	-1,3	***
2021	2,4	1,0	3,8	***	-1,2	-1,6	-0,7	***

* = <0.1 ** = <0.05 *** = <0.01

Two-part model, logistic regression (first part), OLS regression (second part).

Numbers given as average marginal effect (AME) with 95% confidence intervals.

Sociodemographic factors: Days in hospital

Several significant associations were identified between sociodemographic factors and days in hospital. Higher age was strongly negatively associated with days in hospital. Specifically, individuals under 50 year old spent on average 32.5 (95% CI 31.4 – 33.7) days in hospital, 11 more days (95% CI 9.8 – 12.2, p<0.01) than those 71 – 80 years of age, 17.7 more days (95% CI 16.5 – 18.9, p<0.01) than those 81 – 90 years of age, and 23.4 more days (95% CI 22.1 – 24.7, p<0.01) than those >90 years of age. Being married or having a registered partner was positively associated with more days in hospital, with 20.9 days on average in hospital (95% CI 20.7 – 21.2). Those who had previously been married spent 1.4 days fewer (95% CI -1.0 - -1.9, p<0.01), and those who had never been married or had a registered partner spent 1.6 days fewer in hospital (95% CI -1.0 - -2.3, p<0.01) than individuals who were married. Individuals with primary school education spent 19.9 days on average (95% CI 19.5 – 20.2). Individuals with higher education spent 0.8 more days in hospital (95% CI 0.2 – 1.5, p<0.01) compared with those with primary school education only. Higher incomes were associated with more days in hospital. Individuals with an income of 200 - 400 000 NOK spent 19.8 days in hospital (95% CI 19.5 – 20.0), and those with the highest incomes (>800 000 NOK) spent 2.9 more days (95% CI 1.8 – 3.9, p<0.01) more days in hospital. Those with mild or moderate comorbidities spent 20.5 days in hospital (95% CI 20.2 – 20.7), while higher CCI was associated with 0.9 fewer days in hospital (95% CI 0.5 – 1.4, p<0.01). Individuals who died in 2020 and 2021 spent 1.7 days (95% CI 1.3 – 2.2, p<0.01) and 1.2 (95% CI 0.7 – 1.6, p<0.01) fewer days in hospital compared to individuals who died in 2019 (21.2 days, 95% CI 20.8 – 21.5).

Geographic factors

Results from the regression of geographic variables on days at home are presented in Table 3. The full model regression results are presented in Appendix A. Model 1 showed that in fully adjusted regression using only municipality population size, municipality size was positively correlated with days at home. Individuals from the 20% largest municipalities spent 5.2 more days at home (95% CI 1.6 – 8.7 p<0.01) compared to individuals from the 20% smallest municipalities who spent 118.8 days at home on average. Model 2 showed variation in the number of days at home across the counties. Individuals from Agder county spent on average 8.5 fewer days at home (95% CI 6.3 – 10.7, p<0.01) compared to individuals from Oslo county, who spent on average 121.7 days at home (95% CI 119.7 – 123.6). Individuals from Vestfold og Telemark spent 2.7 days more at home (95% CI -0.1 – 5.4, p<0.1), and Viken county spent 5.4 more days (95% CI 3.1 – 7.8, p<0.01) at home compared to individuals from Oslo. Individuals from Rogaland spent on average 2.4 fewer days at home (95% CI -5.2 – 0.4, p<0.1) compared with individuals from Oslo.

Model 3 showed a significant correlation between distance in km from the geographic center of each municipality to the nearest hospital with the number of days spent at home. The linear relationship between distance to the hospital and days at home was supported by the significant main effect, while the significant quadratic term (p<0.01) indicates a curvilinear component in this relationship. The main negative effect became increasingly robust when controlling for municipality size (-0.064, 95% CI -0.100 - -0.028, p<0.01) and county (-0.055, 95% CI -0.092 - -0.017, p<0.01) in separate analyses (model 6). Model 7 displays the results for the complete regression which included municipality size, county and distance to nearest hospital. Regression results show there remains a strong association between distance to nearest hospital and days at home (-0.057, 95% CI -0.097 - -0.017, p<0.01) when municiality size and county are adjusted for. At 10 km distance, individuals spent on average 124.9 days (95% CI 123.9 – 125.9) at home, compared to 122.7 days (95% CI 121.6 – 123.7) at 50 km distance, and 120.1 days (95% CI 117.4 – 122.7) at 90 km distance. Notably, there was no longer a significant association between municipality size and days at home when distance to hospital was adjusted for (p>0.05).

Results from the regression of geographic variables on days in hospital are presented in Table 4. Model 1 showed that in fully adjusted regression using only municipality population size, municipality size was not significantly associated with days in hospital. Model 2 using only county on days in hospital showed significant variation in the number of days at home across all 11 counties (p<0.01). Model 3 using only distance to nearest hospital on days in hospital showed significant negative association (p>0.01). When regressing both county and municipality size on days in hospital in model 4, the increase in days in hospital for individuals in the two largest quintiles in terms of municipality size were 1.6 days (95% CI 0.5 – 2.8, p<0.01) and 1.3 days (95% CI 0.0 – 2.5, p<0.05) more in hospital, respectively, compared to 18.8 days on average (95% CI 17.7 – 20.9) for individuals in the smallest quintile. In complete regression using all three geographic variables (model 7), only distance to nearest hospital (p>0.01) and county were significantly associated with days in hospital. At 10 km distance, individuals spent on average 20.9 days (95% CI 20.5 – 21.2) at home, compared to 19.7 days (95% CI 19.4 – 20.0) at 50 km distance, and 18.6 days (95% CI 17.8 – 19.3) at 90 km distance.

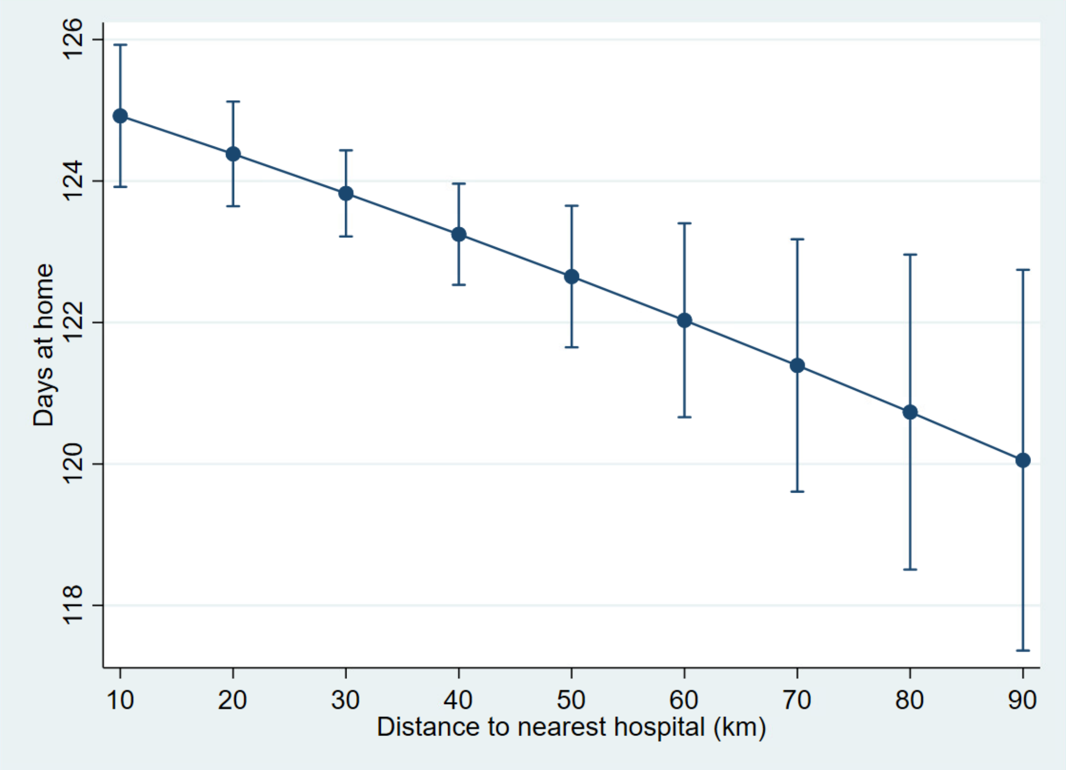

Figure 3. Days at home in last six months of life from the fully adjusted two-part regression model.

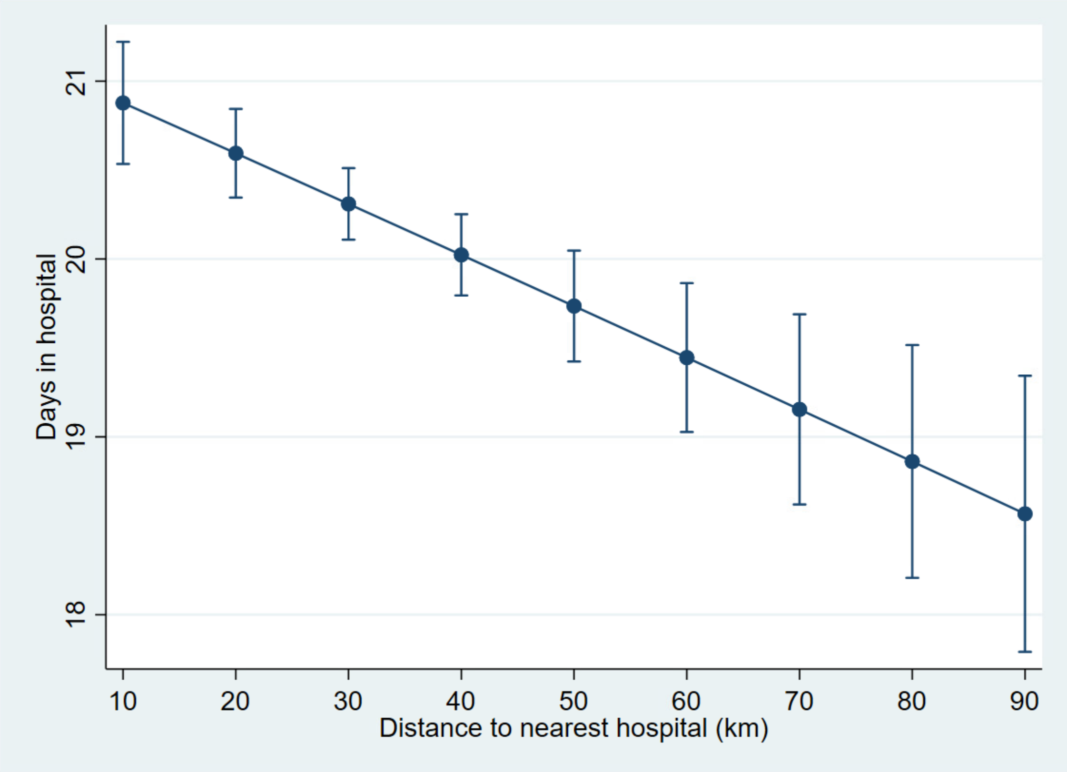

Figure 4. Days in hospital in last six months of life from the fully adjusted two-part regression model.

Stratified analysis

Descriptive statistics showed that men on average spent 127.4 days at home compared to 119.0 days at home for women. See Appendix B for stratified analyses by sex for days at home and in hospital. The average number of days at home for female decedents was the same as for male decedents in the <50 years old group (134.4 days). However, when comparing older cohorts, the number of days at home decreased at a steeper rate with age for women than for men. Already from age 71, women spent 8.2 (95% CI 4.0 – 12.3) fewer days at home than women <50. Men in the same age bracket spent only 0.9 (95% CI -3.5 – 5.3) fewer days at home compared to their <50 year old counterparts. At age 81 – 90, female decedents spent 112 days (95% CI 108.1 – 116.9) at home, compared to 120.4 (95% CI 115.8 – 124.9) for males in the same age bracket. At age >90, female decedents spent 88.9 (95% CI 83.6 – 94.2) days at home, compared to 102.4 (95% CI 97.0 – 107.9) days for males in the same age bracket. Time at home increased more at higher incomes for women than men, but the absolute days remained lower for women across all income brackets compared to men in the same income bracket. Regional variations by county were more pronounced for men, while distance to the nearest hospital had a greater effect for women (-0.081 days per additional km, 95% CI -0.018 - -0.144, $p<0.05$) compared to men (-0.040 days per additional km, 95% CI 0.011 - -0.091, NS). Municipality size was not significantly associated with days at home for men nor women, but living in the most populated municipality was significantly associated with more days in hospital (2.4 days, 95% CI 0.1 – 4.6), $p>0.01$ for women.

DISCUSSION

Main findings

This retrospective registry-based study identified 32 710 cancer-related deaths in Norway between 2018 and 2021, with lung, colon, prostate, and breast cancers being the leading causes. The regression analyses explored the associations between sociodemographic and geographic factors and the number of days spent at home and in the hospital, in the last six months of life. On average, individuals spent 123.5 days at home and 20.4 days in hospital, 13.8 days in short-term care, and 25.0 days in long-term care. The average distance to the nearest hospital was 31.3 km, with the shortest distances found in Oslo county, and greatest distances in counties in Northern Norway. Larger distance to hospital was negatively correlated with municipality size. In regression analyses, significant positive associations were identified between days at home at EoL and male sex, lower age, being married or having a partner, higher education and income. Larger distances to hospital were associated with fewer days at home. Significant differences were found between counties, Agder and Viken county having the highest number of days at home, and Oslo county having the highest number of days in hospital. Stratified analyses by sex revealed that men spent overall more time at home and in the hospital compared to women, and that regional variations by county were more pronounced for men, while distance to the nearest hospital had a greater effect for women on time at home.

The findings revealed several significant associations between sociodemographic factors and time at home and in hospital. Male decedents spent more days at home, and more days in hospital compared to female decedents. It is a well-established phenomenon that women on average are bigger consumers of healthcare services compared to men (31). In our study, this did not apply to hospital services, but instead to municipal care institutions. When comparing with data from 2009 – 2013, this pattern of women spending less time at home and in hospital, and more time in in long-term and short-term institutions, appears to have been maintained over time (16). Being married or having a registered partner was associated with more days at home, but also more days in the hospital. Individuals who were married spent as much as 25 more days at home in the six-month period compared to individuals who had never been married. The importance of having access to informal care to facilitate living at home has been well-documented in previous research (13, 32). The presence of a practical and emotional support system at home may also depend on age. Individuals >80 years old spent significantly less time at home compared to the younger cohorts, which may be attributed to poor health of the patient themselves, but also their spouse. Younger patients may have a familial support system that is better equipped to take on the practical caregiver role, thus enabling the patient to live at home for longer.

Our findings shed light on the barriers faced by individuals residing in rural or remote areas in accessing healthcare services. Our findings indicate that easier access to healthcare services in terms of place of residence is an independent predictor of more time at home. Conversely, rurally located individuals spent less time in hospital compared to those who lived in more urban areas closer to a hospital. Regression analyses showed that distance to hospital had the largest impact on days in hospital, more so than living in a municipality with a small popoulation. However, municipality size and distance to hospital were closely related, meaning that travel time increased as population size decreased. We found that longer distances to a hospital, and by extension living in a smaller municipality, was associated with fewer days at home. This may seem counterintuitive at first glance, and stands in contrast to some previous research from other countries. One registry study from 2020 of over 130 000 Swedish cancer decedents found that individuals living in a rural setting were more likely to have a home death compared to urban individuals (33). Our findings could be due to several factors. In areas with long travel distances to urgent medical care, it may not be feasible for a terminally ill patient to live at home due to concerns with the patient’s safety and comfort. Secondly, individuals living in urban areas may have better access to short-term facilities that can periodically provide relief and support for the sick individual and their family. It may therefore be interpreted that time in hospital and in municipal care institutions are substitutes. In remote areas, such facilities may not be available, or be difficult to access (34).

Some regions are more affected by these inequalities than others. Northern regions, such as Troms og Finnmark and Nordland, had the longest distances to hospital, and were therefore more likely to be admitted to municipal care institutions. However, not all variation in days at home and in hospital was explained by rurality and distance to healthcare services. We also found unexplained differences between the counties. Some regions including Agder, Viken, and Trøndelag, displayed consistently more days at home compared to other regions. This could potentially be explained by better access to other healthcare services, like the availability of home-based nursing or access to short-term and long-term care institutions. (35). Previous research in a cancer context in Norway has identified regional variations in clinical outcomes, such as prognosis and mortality (18). Regional differences have also been identified for waiting times for cancer treatments, with varied wait times depending on treatment type (surgery, radiotheraphy and others) (36). In addition to healthcare accessibility disparities, regional variation in healthcare utilization uncovered in this study may also be due to demand factors, such as patient preferences. Culture can vary according to region, and influence the individual's perceived need for healthcare services. This may also hold true for culture among healthcare professionals across different regions. Attitudes towards the appropriate place to be cared for at EoL may therefore influence both the demand side and supply side to healthcare services utilization.

Policy implications

Each individual has the right to equitable healthcare services where they are located. However, provision of high-quality care in the rural districts is challenging from a health policy perspective. Financial barriers, lack of specialist healthcare professionals working in these areas, and low population density means that inhabitants often rely on primary healthcare services, in particular their general practitioner, for the majority of their healthcare needs. However, these populations often face severe shortages of primary care providers (34). Research on facilitators of living at home at EoL has highlighted support from palliative units and teams as an important facilitator of living at home (2, 8, 33). As a result of *Samhandlingsreformen*, a reform which reorganized the responsibilities of the healthcare services and delegated several previous state tasks to the municipalities, primary responsibility of the provision of palliative care was transferred to the municipalities in 2009. However, a report from 2022 uncovered that only one out of ten municipalities has a palliative unit (37). Discrepancies between the available healthcare facilities and services across regions and municipalities impose important structural challenges. Inaccessibility due to geographic factors is therefore a central issue facing the healthcare sector, and policy regarding EoL for individuals with cancer needs to consider these inequalities. By identifying the significance of these geographic factors, policymakers and healthcare providers may develop targeted interventions and policies to address disparities and improve access to EoL care.

Strengths and limitations

This study has several important strengths. First, this was the first study using updated data from recent years to assess the impact of geographic factors on healthcare utilization and time spent at home in the final months of life for cancer individuals in Norway. The study had information on each individual's place of residence up until death. Second, detailed information on both primary care and specialist care utilization was obtained through linking registries, which allowed for a comprehensive overview of each individual individual's medical history. The completeness of the NPR and NRPC is reported to be high (38). Third, there were no selection bias concerns, given that the registries automatically obtains data on the relevant population, and individuals therefore do not have to opt in. This is a major strength of Nordic national registries, which allows for large epidemological studies of high quality. This allows us to draw conclusions about EoL cancer care at for Norwegian individuals with cancer as a whole.

This study involves some limitations. First, coordinates for municipality centers were not available for 11% of municipalities, which may have affected our estimates somewhat. Second, other factors related to place of residence, such as the income and wealth of each municipality authority, existence of short-term institutions and palliative care teams, may be other important factors that were not included in this study. Further research may explore more in-depth the characteristics of the municipalities to assess their importance. Lastly, explicit individual preferences are not accounted for in this study. Discussions about preferences and goals for EoL are essential parts of high-quality care, and further research may explore the significance of individual preferences in predicting time at home in EoL care when geographic limitations are also considered (39).

CONCLUSION

This study has evaluated the geographic implications in healthcare use among individuals with cancer at EoL. Better access to healthcare services in terms of place of residence, including living close to a hospital and in an urban location, are independent predictors of more time spent at home. Factors including as sex, age, marital status, education, income, municipality size, county of residence, and distance to the nearest hospital all play a role in determining healthcare service use at EoL. Living closer to a hospital was an independent predictor of spending more time in hospital. In summary, these findings highlight the influence of sociodemographic and geographic factors on care patterns at the end of life for cancer individuals in Norway.

References

1. Raknes G. Tall fra Dødsårsaksregisteret 2021: Folkehelseinstituttet; 2022 [Available from: https://www.fhi.no/hn/helseregistre-og-registre/dodsarsaksregisteret/tall-fra-dodsarsaksregisteret-2021/.
2. Higginson IJ, Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. Journal of palliative medicine. 2000;3(3):287-300.
3. Sayer C. “Time spent at home”—a patient-defined outcome. NEJM Catalyst. 2016;2(2).
4. Institute NC. End-of-life care [Available from: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/end-of-life-care.
5. omsorgsdepartementet H-o. Norges offentlige utredninger 2017: 16. På liv og død: Palliasjon til alvorlig syke og døende.
6. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC palliative care. 2013;12(1):1-13.
7. Peters L, Sellick K. Quality of life of cancer patients receiving inpatient and home-based palliative care. Journal of advanced nursing. 2006;53(5):524-33.
8. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ, de Brito M. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews. 2013(6).
9. Yadav S, Heller IW, Schaefer N, Salloum RG, Kittelson SM, Wilkie DJ, et al. The healthcare cost of palliative care for cancer patients: a systematic review. Supportive Care in Cancer. 2020;28:4561-73.
10. Thorn JC, Turner EL, Hounsome L, Walsh E, Down L, Verne J, et al. Validating the use of Hospital Episode Statistics data and comparison of costing methodologies for economic evaluation: an end-of-life case study from the Cluster randomised triAl of PSA testing for Prostate cancer (CAP). BMJ open. 2016;6(4):e011063.
11. Larsson K, Kåreholt I, Thorslund M. Care utilisation in the last years of life in relation to age and time to death: results from a Swedish urban population of the oldest old. European Journal of Ageing. 2008;5:349-57
12. Kjellstadli C, Husebø 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):1-11.
13. Khan SA, Gomes B, Higginson IJ. End-of-life care—what do cancer patients want? Nature reviews Clinical oncology. 2014;11(2):100-8.
14. McPherson CJ, Wilson KG, Murray MA. Feeling like a burden: Exploring the perspectives of patients at the end of life. Social science & medicine. 2007;64(2):417-27.
15. Johansson CM, Axelsson B, Danielson E. Living with incurable cancer at the end of life-patients' perceptions on quality of life. Cancer Nursing. 2006;29(5):391-9 %.
16. Bjørnelv G, Hagen TP, Forma L, Aas E. Care pathways at end-of-life for cancer decedents: registry based analyses of the living situation, healthcare utilization and costs for all cancer decedents in Norway in 2009-2013 during their last 6 months of life. BMC Health Services Research. 2022;22(1):1221.
17. Andersen SK, Croxford R, Earle CC, Singh S, Cheung MC. Days at home in the last 6 months of life: A patient-determined quality indicator for cancer care. Journal of oncology practice. 2019;15(4):e308-e15.
18. Skyrud KD, Bray F, Eriksen MT, Nilssen Y, Møller B. Regional variations in cancer survival: Impact of tumour stage, socioeconomic status, comorbidity and type of treatment in N orway. International journal of cancer. 2016;138(9):2190-200.
19. Ammitzbøll G, Levinsen AKG, Kjær TK, Ebbestad FE, Horsbøl TA, Saltbæk L, et al. Socioeconomic inequality in cancer in the Nordic countries. A systematic review. Acta Oncologica. 2022;61(11):1317-31.
20. Koay K, Schofield P, Jefford M. Importance of health literacy in oncology. Asia-Pacific Journal of Clinical Oncology. 2012;8(1):14-23.
21. Helsedirektoratet. Om pakkeforløpet 2022 [Available from: https://www.helsedirektoratet.no/nasjonale-forlop/hjem-for-pasienter-med-kreft/om-pakkeforlopet.

22. sentralbyrå S. Om oss [Available from: https://www.ssb.no/en/omssb/om-oss.
23. Health NDo. Norwegian Patient Registry (NPR) [Available from: https://helsedata.no/en/forvaltere/norwegian-directorate-of-health/norwegian-patient-registry-npr/.
24. Helsedirektoratet. Kommunalt pasient- og brukerregister (KPR) [Available from: https://www.helsedirektoratet.no/tema/statistikk-registre-og-rapporter/helsedata-og-helseregistre/kommunalt-pasient-og-brukerregister-kpr.
25. Folkehelseinstituttet. Om Dødsårsaksregisteret 2014 [Available from: https://www.fhi.no/hn/helseregistre-og-registre/dodsarsaksregisteret/dodsarsaksregisteret2/.
26. Charlson ME, Carrozzino D, Guidi J, Patierno C. Charlson comorbidity index: a critical review of clinimetric properties. Psychotherapy and psychosomatics. 2022;91(1):8-35.
27. Kartverket. Om Kartverket. [Available from: https://www.kartverket.no/om-kartverket.
28. Burnham KP, Anderson DR. Multimodel inference: understanding AIC and BIC in model selection. Sociological methods & research. 2004;33(2):261-304.
29. Committees NRE. Retningslinjer for inklusjon av kvinner i medisinsk forskning Oslo. 2001 [Available from: https://www.forskningsetikk.no/retningslinjer/med-helse/inklusjon-av-kvinner/.
30. Editors TiCoMJ. Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals. 2022.
31. Lunde ES, Ramm JS, Syse A. Kvinners liv og helse siste 20 år. Statistisk sentralbyrp; 2022.
32. Bjørnelv GMW, Edwin B, Fretland ÅA, Deb P, Aas E. Till death do us part: the effect of marital status on healthcare utilization and costs at end-of-life. A register study on all colorectal cancer decedents in Norway between 2009 and 2013. BMC health services research. 2020;20(1):1-13.
33. Nilsson J, Axelsson B, Holgersson G, Carlsson T, Bergqvist M, Bergstrom S. Geographical Differences in Likelihood of Home Death Among Palliative Cancer Patients: A National Population-based Register Study. Anticancer Research. 2020;40(7):3897-903.
34. Devik SA, Hellzèn O. Palliasjon i rurale strøk: lindrende omsorg for eldre kreftpasienter som bor hjemme. En systematisk litteraturstudie. 2013.
35. Finkelstein A, Gentzkow M, Williams H. Sources of geographic variation in healthcare: Evidence from patient migration. The quarterly journal of economics. 2016;131(4):1681-726.
36. Nilssen Y, Eriksen MT, Guren MG, Møller B. Factors associated with emergency-onset diagnosis, time to treatment and type of treatment in colorectal cancer patients in Norway. BMC cancer. 2021;21(1):1-18.
37. Trier EL, Haugland T, Thoresen L. Palliative enheter i de kommunale helse-og omsorgstjenestene–en kartleggingsstudie. Tidsskrift for omsorgsforskning. 2022(3):1-19.
38. Bakken IJ, Ariansen AMS, Knudsen GP, Johansen KI, Vollset SE. The Norwegian Patient Registry and the Norwegian Registry for Primary Healthcare: Research potential of two nationwide health-care registries. Scandinavian journal of public health. 2020;48(1):49-55.
39. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. JAMA internal medicine. 2014;174(12):1994-2003.

Appendix A. Fully adjusted regression model with geographic variables.

.	Days at home				Days in hospital.			
	Beta/ days	**Lower 95% CI**	**Upper 95% CI**	**p-value**	**Beta/ days**	**Lower 95% CI**	**Upper 95% CI**	**p-value**
Sex								
Male (ref)	124.8	123.9	125.9		20.4	20.1	20.7	
Female	-2.4	-3.7	-1.1	***	-0.3	-0.8	0.1	
Age								
<50 (ref)	135.0	132.2	137.8		32.9	31.7	34.1	
51-60	1.6	-1.6	4.9		-4.5	-5.9	-3.2	***
61-70	-0.7	-3.7	2.3		-7.1	-8.4	-5.9	***
71-80	-5.0	-7.9	-2.0	***	-11.4	-12.6	-10.1	***
81-90	-18.4	-21.5	-15.3	***	-18.1	-19.3	-16.8	***
>90	-39.0	-42.8	-35.3	***	-23.9	-25.2	-22.5	***
Marital status								
Married or registered partner (ref)	134.2	133.3	135.0		21.1	20.8	21.4	
Previously married or registered partner	-18.1	-19.5	-16.8	***	-1.6	-2.0	-1.1	***
Never married	-24.5	-27.0	-22.0	***	-2.2	-2.9	-1.5	***
Years of completed education								
10 years (primary school) (ref)	122.9	121.8	123.9		20.0	19.7	20.4	
13 years (high school)	1.4	-0.2	2.7	*	0.2	-0.2	0.7	
>13 years (higher education)	1.7	-0.3	3.8	*	0.5	-0.2	1.1	
Yearly personal income (NOK)								
Under 200000	1.3	-1.0	3.7		-0.8	-1.5	-0.0	**
200 - 400 000 (ref)	121.3	120.5	122.2		19.9	19.7	20.2	
400 - 600 000	6.9	5.3	8.6	***	1.1	0.5	1.6	***
600 - 800 000	14.5	11.8	17.2	***	1.2	0.3	2.1	**
>800 000	14.3	11.3	17.4	***	2.3	1.2.0	3.4	***
CCI*								
Mild/ moderate (ref)	123.0	122.3	123.8		20.6	20.3	20.8	
Severe	3.3	1.9	4.7	***	-1.3	-2.0	-0.5	***
Year of death								
2019 (ref)	122.1	121.1	123.2		21.2	20.9	21.6	
2020	2.1	0.6	3.6	***	-1.8	-2.3	-1.3	***
2021	2.5	1.0	4.0	***	-1.2	-1.7	-0.7	***
Municipality inhabitant size								
<=1857	121.0	116.7	125.3		19.1	17.7	20.6	
1858 - 3427	2.7	-2.3	7.7		0.4	-1.3	2.0	
3428 - 6810	3.5	-1.2	8.1		0.8	-0.7	2.4	

6810 - 17316	3.1	-1.5	7.7		1.0	-0.6	2.5	
>17316	2.6	-1.8	7.1		1.3	-0.2	2.8	*
County (fylke)								
Oslo (ref)	121.0	117.1	121.3		23.4	22.7	24.0	
Agder	8.5	5.3	11.8	***	-7.5	-8.6	-6.5	***
Innlandet	2.4	-0.6	5.5		-4.8	-5.8	-3.8	***
Møre og Romsdal	-0.8	-4.6	3.1		-3.6	-4.9	-2.4	***
Nordland	0.7	-3.0	4.4		-1.3	-2.5	-0.4	**
Rogaland	-1.8	-4.8	1.1		-1.0	-2.0	-0.1	**
Troms og Finnmark	1.0	-2.8	4.7		-1.3	-2.5	-0.1	**
Trøndelag	3.4	0.3	6.1	**	-2.1	-3.1	-1.2	***
Vestfold og Telemark	3.3	0.5	6.1	**	-4.3	-5.2	-3.4	***
Vestland	-0.1	-3.0	2.9		-0.9	-1.8	0.1	*
Viken	6.2	3.8	8.6	***	-4.9	-5.7	-4.1	***
Distance from nearest hospital								
Kilometers (continuous)	-0.058	-0.098	-0.017	***	-0.052	-0.073	-0.031	***
Kilometers^2	0.000	0.000	0.000	**	0.000	0.000	0.000	***
At 10 kilometers	124.9	123.9	125.9	-	20.9	20.5	21.2	-
At 20 kilometers	124.4	123.6	125.1	-	20.6	20.3	20.8	-
At 30 kilometers	123.8	123.2	124.4	-	20.3	20.1	20.5	-
At 40 kilometers	123.2	122.5	124.0	-	20.0	19.8	20.3	-
At 50 kilometers	122.7	121.6	123.7	-	19.7	19.4	20.0	-
At 60 kilometers	122.0	120.7	123.4	-	19.4	19.0	19.9	-
At 70 kilometers	121.4	119.6	123.2	-	19.2	18.6	19.7	-
At 80 kilometers	120.7	118.5	123.0	-	18.9	18.2	19.5	-
At 90 kilometers	120.1	117.4	122.7	-	18.6	17.8	19.3	-

N = 28 529. AIC/BIC = 268 662.8/269 174.9
* = <0.1 ** = <0.05 *** = <0.01

Two-part model, logistic regression (first part), OLS regression (second part). Numbers given as average marginal effect (AME) with 95% confidence intervals.

Appendix B. Regression results stratified by sex.

	Days at home								Days in hospital.							
	Female				**Male**				**Female**				**Male**			
	Beta/ days	**Lower 95% CI**	**Upper 95% CI**	**p-value**	**Beta/ days**	**Lower 95% CI**	**Upper 95% CI**	**p-value**	**Beta/ days**	**Lower 95% CI**	**Upper 95% CI**	**p-value**	**Beta/ days**	**Lower 95% CI**	**Upper 95% CI**	**p-value**
Age																
<50 (ref)	134.4	130.6	138.2		134.4	130.2	138.5		32.4	30.9	34.0		33.3	31.5	35.2	
51-60	0.4	-4.1	4.9		3.8	-1.0	8.6		-3.7	-5.5	-2.0	***	-5.3	-7.4	-3.2	***
61-70	-2.4	-6.6	1.8		2.1	-2.3	6.5		-6.5	-8.2	-4.9	***	-7.6	-9.5	-5.7	***
71-80	-8.2	-12.3	-4.0	***	-0.9	-5.3	3.5		-11.6	-13.2	-9.9	***	-11.2	-13.1	-9.3	***
81-90	-22.0	-26.3	-17.6	***	-14.0	-18.6	-9.5	***	-18.2	-19.9	-16.6	***	-18.0	-19.9	-16.0	***
>90	-45.5	-50.8	-40.2	***	-32.0	-37.4	-26.5	***	-24.6	-26.4	-22.8	***	-23.2	-25.3	-21.1	***
Marital status																
Married or registered partner (ref)	131.9	130.3	133.4		136.0	135.0	137.0		20.5	20.0	21.0		21.5	21.2	21.9	
Previously married or registered partner	-18.4	-20.7	-16.2	***	-17.5	-19.4	-15.6	***	-1.2	-1.9	-0.5	***	-1.7	-2.3	-1.1	***
Never married	-25.7	-29.8	-21.5	***	-23.1	-26.3	-20.0	***	-1.6	-2.6	-0.5	***	-2.6	-3.5	-1.7	***
Years of completed education																
10 years (primary school) (ref)	117.8	116.3	119.4		127.4	126.0	128.9		19.6	19.1	20.1		20.5	19.9	21.0	
13 years (high school)	1.9	-0.1	4.0	*	0.9	-1.0	2.7		0.1	-0.5	0.8		0.3	-0.4	1.0	
>13 years (higher education)	3.4	0.3	6.5	**	0.3	-2.4	3.0		0.4	-0.5	1.3		0.4	-0.5	1.3	
Yearly personal income (NOK)																
Under 200000	2.5	-0.5	5.5		-0.3	-5.0	4.4		-0.6	-1.5	0.3		-0.3	-1.8	1.2	
200-400 000 (ref)	117.1	115.9	118.2		125.0	123.9	126.2		19.5	19.1	19.8		20.3	19.9	20.7	
400 - 600 000	7.6	4.8	10.4	***	6.5	4.4	8.5	***	1.6	0.8	2.5	***	0.7	-0.1	1.4	*
600 - 800 000	17.0	12.2	21.8	***	12.9	9.8	16.1	***	1.6	0.0	3.1	**	1.0	-0.2	2.2	*
>800 000	16.0	9.3	22.7	***	13.3	10.0	16.5	***	2.6	0.5	4.7	**	2.4	1.1	3.6	***
CCI*																

Mild/moderate (ref)	118.1	117.0	119.2		127.5	126.6	128.4		20.2	19.9	20.6		20.9	20.6	21.3	
Severe	5.2	3.0	7.3	***	1.6	-0.2	3.5	*	-1.6	-2.2	-0.9	***	-0.8	-1.4	-0.2	**
Year of death																
2019 (ref)	117.6	116.1	119.2		126.2	124.8	127.6		20.9	20.4	21.3		21.6	21.1	22.1	
2020	2.2	-0.1	4.5	*	2.1	0.1	4.0	**	-1.8	-2.5	-1.1	***	-1.7	-2.4	-1.0	***
2021	2.2	-0.1	4.4	*	2.8	0.8	4.8	***	-1.5	-2.2	-0.8	***	-0.9	-1.6	-0.2	**
Municipality inhabitant size																
<=1857 (ref)	115.2	108.1	122.3		126.0	120.6	131.3		17.5	15.3	19.6		20.3	18.4	22.2	
1858 - 3427	3.9	-4.1	12.0		1.7	-4.5	8.0		1.9	-0.6	4.4		-0.7	-3.0	1.5	
3428 - 6810	4.2	-3.4	11.8		2.9	-2.9	8.7		2.2	-0.2	4.5	*	-0.1	-2.2	2.0	
6810 - 17316	2.3	-5.2	9.8		3.9	-1.8	9.6		2.3	0.0	4.6	*	0.2	-1.9	2.2	
>17316	4.3	-3.0	11.5		1.4	-4.2	6.9		2.4	0.1	4.6	**	0.6	-1.4	2.6	
County (fylke)																
Oslo (ref)	117.7	114.6	120.9		123.9	121.1	126.7		22.6	21.7	23.6		24.0	23.1	25.0	
Agder	7.0	1.9	11.9	***	9.9	5.7	14.2	***	-8.0	-9.4	-6.5	***	-7.1	-8.6	-5.7	***
Innlandet	-0.2	-4.8	4.3		4.9	0.8	8.9	**	-4.6	-6.0	-3.3	***	-4.9	-6.3	-3.5	***
Møre og Romsdal	-0.7	-6.8	4.8		-0.3	-5.4	4.8		-2.8	-4.6	-1.0	***	-4.3	-6.0	-2.6	***
Nordland	0.8	-4.7	6.4		0.6	-4.4	5.6		-0.3	-2.0	1.5		-2.2	-3.9	-0.5	**
Rogaland	-1.3	-5.7	3.0		-2.4	-6.3	1.6		-1.0	-2.4	0.3		-1.1	-2.4	0.3	
Troms og Finnmark	-2.9	-8.7	2.6		4.6	-0.5	9.7	*	-0.2	-1.9	1.5		-2.5	-4.2	-0.8	***
Trøndelag	1.6	-2.9	6.2		5.0	0.9	9.0	**	-1.8	-3.2	-0.4	**	-2.4	-3.8	-1.1	***
Vestfold og Telemark	1.2	-3.1	5.4		5.2	1.4	8.9	***	-4.2	-5.5	-2.8	***	-4.5	-5.7	-3.2	***
Vestland	1.0	-3.4	5.4		-1.0	-4.9	2.9		-0.8	-2.2	0.6		-0.8	-2.2	0.5	
Viken	3.6	0.0	7.2	*	8.6	5.4	11.8	***	-4.7	-5.8	-3.6	***	-5.2	-6.3	-4.0	***
Distance from nearest hospital																
Kilometers (continuous)	-0.081	-0.144	-0.018	**	-0.040	-0.091	0.011		-0.042	-0.061	-0.023	***	-0.016	-0.034	0.002	*
Kilometers^2	0.000	0.000	0.000	**	0.000	0.000	0.000		0.000	0.000	0.000	**	0.000	0.000	0.000	

* = <0.1 ** = <0.05 *** = <0.01

Two-part model, logistic regression (first part), OLS regression (second part).

Numbers given as average marginal effect (AME) with 95% confidence intervals. Results from regression analyses using fully adjusted models (including covariates age, sex, marital status, years of completed education, personal yearly income, comorbidities, year of death).

Appendix C. Conceptual and theoretical framework (kappe).

1.1 Introduction

Cancer remains a major public health problem, and imposes a large burden on the diseased individual, their family, the healthcare system, and society. It is a political aim to provide equitable healthcare for all individuals, irrespective of sex, race, age and location. It is important to understand the degree of healthcare use disparity across different groups, and which factors are implicated in creating these disparities. In this section I will present the conceptual and theoretical frameworks that guided this master's thesis.

1.2 Why geography matters

Norway has a small population of 5.4 million people with low population density (1). The landscape is rugged, with mountains, fjords, forests and lakes, which has shaped the distribution of cities and communities we see today. Major cities like Oslo, Bergen and Trondheim are located in the southern and central parts of the country, while many communities live in relatively geographically isolated areas, especially in the North. Geographical barriers and lack of healthcare professionals in rural areas present significant challenges to meeting the demand for healthcare. Geographic barriers and low population density impose a structural challenge to providing equitable care to populations living in rural areas that are far away from population centers, where facilities like hospitals and large healthcare institutions primarily are located. Compared to smaller countries with less variation in population density across regions, the structure of the Norwegian healthcare system needs to reflect these realities.

1.3 The Norwegian healthcare system

We first need to consider how the healthcare system is organized, and how that may affect an individual's healthcare use. The Norwegian healthcare system is partially decentralized, meaning that responsibility of the healthcare services is split between the state and the municipalities (2). The 356 municipalities are responsible for primary healthcare services, which are funded by the municipalities through taxation and earmarked subsidies by the state (2). The municipalities have a large degree of freedom when it comes to the organization of the primary healthcare services.

The oversight of the healthcare sector is a centralized task that lies with the Ministry of Health and Care Services. The specialist healthcare services are managed by the state, and are structured according to four Regional Health Authorities (RHA, «regionale helseforetak»), each responsible for managing and organizing specialized healthcare services within their respective regions. Each RHA is responsible for the ownership, administration, and planning of the hospitals within its jurisdiction. The authorities ensure that the hospitals in their region have the necessary resources and infrastructure to provide high-quality healthcare services. The authorities coordinate the allocation of funds and oversee the implementation of healthcare policies and strategies. Although the day-to-day management of the hospitals is the responsibility of the RHA, the state has ownership of the hospitals and specialized care services. Political management of the specialist care sector is a governmental responsibility, and is conducted through parliamentary legislation.

The four RHAs in Norway are:

- Northern Norway Regional Health Authority (Helse Nord RHF): This authority serves the northernmost part of Norway. It operates several hospitals, such as the University Hospital of North Norway in Tromsø, which offers a wide range of specialized services to the region.
- Central Norway Regional Health Authority (Helse Midt-Norge RHF): Covering the central part of Norway, this authority manages hospitals like St. Olavs Hospital in Trondheim, which is the largest hospital in the region and provides comprehensive specialized care.
- Western Norway Regional Health Authority (Helse Vest RHF): Responsible for healthcare in the western region of Norway. Helse Vest RHF operates hospitals such as Haukeland University Hospital in Bergen, which is a major teaching hospital and a hub for specialized medical services.
- Southern and Eastern Norway Regional Health Authority (Helse Sør-Øst RHF): This is the largest health region in Norway, serving the southern and eastern parts of the country. In 2013, the health authority served 55% of the population (2). The region manages hospitals like Oslo University Hospital.

Financing

In terms of financing, the Norwegian healthcare system is based on a welfare model, and the degree of public ownership is large. The healthcare system is financed primarily through taxation (86%) (3). Public opinion is largely that the state should be responsible for costs associated with the healthcare needs in the population. The state spent 418 billion NOK on all healthcare related activity, which made up 12.8% of Norway’s GDP in 2021 (3). This percentage has been increasing in recent years, up 0.7 percentage points since 2015. It is expected that demand for healthcare will continue to increase in the coming years and decades (4).

2.1 Cancer

The World Health Organization (WHO) defines cancer as «a large group of diseases that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and/or spread to other organs» (5). The International Classification of Diseases (ICD) is the international standard of classifying cancer diagnoses (6). Prognosis and survival vary by cancer type. Although treatment has come a long way in recent decades and advances are continuously made, cancer remains a deadly disease. In Norway, it is the most common cause of death, just surpassing cardiovascular diseases (7). It is estimated that nearly one of four individuals who are diagnosed with cancer die from the disease (8). Standardized cancer care pathways, «Pakkeforløp for kreft», were introduced in 2015 as part of a nationwide initiative to improve cancer care and ensure timely diagnosis, treatment, and follow-up (9). Introducing a standardized treatment package was done with the aim of reducing unwanted differences in access to fast and high quality of care across hospitals and health regions.

2.1 Cancer is a growing public health problem

Cancer is a common disease group that affects people of all ages, but is most prevalent among older people. The number of cancer cases is at a steady increase, which this is a trend we have seen for many years (8). According to a report by Oslo Economics, 119 744 people visited their general practitioner (GP) in 2020 when cancer was the reason for the visit (4). This is a 50% increase from 2010. An increase can be seen for hospital visits as well. The number of patients at Norwegian hospitals for cancer treatment was up 15% in 2021, compared with in 2017 (4). This incease can be partially attributed to the fact that the population lives longer on average, which means that more people live with illnesses for longer, and an increasing number of people get one or more severe illnesses in their lifetime. In 2060 it is estimated that every fifth person will be above 70 years of age (1). If the demographic change we are experiencing in terms of an aging population maintains its course, cancer will become an increasingly costly burden on our public healthcare system in the years to come.

2.2. Sociotal costs associated with cancer

In addition to the burden of living with cancer for the patient themselves and their surroundings, cancer is associated with large societal costs, through direct medical costs, productivity losses, and social welfare payouts. There is large variation in the societal costs associated with different cancer types due to differences in prevalence, treatment, severity, prognosis, etc. For example, costs associated with breast, cervival, and pancreatic cancer are associated with large productivity losses du eto inability to work and loss of income (4). Cancers that are associated with poor prognosis are associated with productivity losses due to death. In comparison, some cancer types are associated with high treatment costs, like urinary tract cancers and prostate cancer (4).

2.3 End-of-life care in cancer

End-of-life (EoL) cancer care focuses on providing comprehensive support and care to patients during the terminal stages of their illness. It aims to manage symptoms, enhance quality of life, address psychosocial and spiritual needs, and support patients and their families through the last phase of the illness. The primary goal is often symptom management. National guidelines are in place to assist healthcare professionals with caring for terminally ill patients at EoL (10). In this study I chose to focus on the final six months of life to capture healthcare use in the terminal stage of illness. This was supported by existing literature on end-stage cancer (11, 12, 13). As a patient's life expectancy is around the six month mark, they will often no longer undergo active treatment, and the treatment goals shift to palliative and supportive care (14). In the United States, for example hospice care is typically covered by insurance (Medicare) in the predicted last six months of life.

2.4. Patient preferences

There is much debate surrounding the appropriate place to be cared for at EoL. Qualitative studies give us insight into the patients' own thoughts on the matter. A literature search revealed patient preferences to be favorable of home death (12, 15, 16, 17). However, this preference is dependent on several factors. Sufficient assistance from healthcare personnel, presence of caregivers at home, and trust in the competence and expertise of the healthcare professionals surrounding the patient are important facilitators of time at home in the final stage of life (18). It is important to be cogniscent of the factors that impact patient preferences from a policy perspective, to ensure that the patient has equitable grounds to make decisions regarding their care that align with their personal comfort levels and goals.

2.5 Political aims and patient rights

It is a political aim to ensure that the individual is able to live where they wish, also at EoL. *Meld. St. 24 (2019 – 2020) Lindrende behandling og omsorg* outlines national policy on palliative treatment and care, and states that the individual should have freedom of choice to decide where they want to stay in the final phase of life, and where they wish to die (19). Provision of care by the municipal healthcare services may be done in the patient's home to facilitate home-living and home death. This may include home-based nursing services, help with day-to-day living tasks like hygienic personal care, cleaning, cooking, and shopping, thereby enabling the patient to stay in their own homes. Depending on need, this may be offered several times a day. If the patient lives at home, the general practitioner has primary responsibility for the patient. Many municipalities have an alleviating/palliative unit. A palliative unit in the municipality is an offer to patients who do not have the opportunity to receive care in own home, who needs relief, or needs help to improve symptom control. These units offer to patients with a larger and more complex need for palliative treatment, care and care than the usual long-term wards or short-term departments can offer.

Methods

3.1. Patient registries.

The individual-level data used in this study was obtained from four electronic registries and linked with a unique identification number. The registries were Statistics Norway, the Norwegian Patient Registry (NPR), the Norwegian Registry for Primary Healthcare (NRPC), and the Norwegian Causes of Death Registry. The registries were created based on legislative rulings that allow for the collection of sensitive personal identifiable information without consent, which means that the registries can contain information on the entire Norwegian population.

Statistics Norway, known as "Statistisk sentralbyrå" (SSB) in Norwegian, is the national statistical agency of Norway. It is an independent institution responsible for collecting, analyzing, and disseminating official statistics about various aspects of Norwegian society, including population, economy, labor market, social conditions, environment, and more. Established in 1876, Statistics Norway operates under the Ministry of Finance and is governed by the Statistics Act. Statistics Norway employs data linkage techniques to combine and analyze data from different sources, and link individual-level data from surveys, administrative registers, and censuses. Data linkage is conducted while adhering to privacy and confidentiality guidelines to ensure individual privacy.

The NRPC is a comprehensive electronic registry that is maintained at the municipal level in Norway, and was established by the Directorate of Health in 2017. It is designed to collect and store healthcare-related information about patients and users of municipal health and care services. The NPR is a nationwide registry that collects information about patient encounters with the Norwegian specialized healthcare system, and it is frequently used in health research. It is managed by the Norwegian Institute of Public Health (Folkehelseinstituttet). The registry contains various types of data related to patient care, including medical diagnoses and procedures according to diagnosis-related group codes, which are standardized across all Norwegian hospitals. ICD-codes are used to classify and categorize medical conditions, providing a standardized method for data collection and analysis. The registry contains data on hospital admissions, including the dates of admission and discharge, the department or unit where the patient was treated, and the reason for admission. It also provides information about outpatient visits. The registry captures data on various medical procedures, interventions, and treatments performed during patient encounters.

3.2. Theoretical framework: Andersen Behavioral Model of Health Service Utilization

The main objective of this study was to identify which factors influence healthcare use among people with cancer. The Andersen Behavioral Model of Health Service Utilization (Anderson model) was used as a theoretical framework to decide which factors to investigate in regression analyses. (20). The Andersen model can be used to examine the factors that influence someone to need and seek out medical care, and was developed to study the determinants of health service utilization, and assess inequality in health services access. Equitable access to healthcare services is achieved when demographic characteristics and needs are the largest determinants of variations in use (21). Inequitable access, in comparison, arises when social characteristics, health beliefs, and enabling resources account for the majority of variations in usage. The Andersen model consists of three core components that are suggested to influence individuals' healthcare use: predisposition, enabling or impeding factors related to accessing services, and the indivudual's care needs. The components follow a pathway in which predisposing factors influence enabling factors, which in turn influence need. These factors are places in an organizational context to account for macro and meso-level factors, including healthcare schemes and systems, as well as state and local policy. The model has been previously applied in studies of cancer populations to investigate disparities across groups in health services use (22, 23). The following paragraphs will discuss the main facets of the model as it relates to the present study and the selection of variables.

3.2.1. Predisposing factors

The first component of Andersen's model to influence healthcare use is predisposition. Predisposing characteristics are factors that influence health status and impact the likelihood of a person requiring and using healthcare services (21). They typically refer to the individual's demographic, social characteristics, and health beliefs. Such factors may be out of the person's control, such as age, race and sex (21). Literature searches revealed well established associations between age and sex with time at home at EoL, and these variables were available to be included in this study (21, 24). Statistics Norway does not currently obtain race or ethnicity-related information on inhabitants. Other predisposing factors include sociodemographic factors such as marital status, occupation, and education. Being married or having a live-in partner is strong indicator of having a familial support system, which is crucial for the ability to live at home at EoL (25). Supporting this reasoning, registry-based studies of cancer patients in Norway have found strong associations between time at home and marital status (11, 26). Interestingly, there has been shown a marked difference in healthcare use between those who were divorced or separated from their partner and those who have never been married. As previously married individuals are more likely to have children, this supports the use of marital status as a proxy for care assistance in the home. In the present study I wanted to investigate whether this finding would be replicated.

The link between socioeconomic status, including education and income, with health literacy is well-established. In healthcare systems with private healthcare, higher income would perhaps be associated with less time at home, given the relative accessibility of healthcare institutions, and higher opportunity cost of the working spouse of staying home to take on care responsibilities. Alternatively, costs associated with having home care would be paid out-of-pocket by the patient's family. In such scenarios, the link between socioeconomic status and healthcare use is clear, and may be considered an enabling or impeding factor of accessing healthcare according to the Andersen model. However, in a system like Norway’s, where the patient and their family does not directly take on the cost of medical care, the effect of income and education on healthcare utilization manifests for other reasons than cost of care. Higher socioeconomic status may for example influence patient preferences through increasing the likelihood that the patient has a stable and safe home environment with sufficient space and resources (27). Research on socioeconomic status and its implication in health has shown that health literacy, meaning the knowledge, skills and abilities that pertain to interactions with the healthcare system, functions as a mediating factor in the relationship between socioeconomic status and health disparities (28). Comparatively higher levels of health literacy in high education and high income groups may therefore explain some of the disparity we see in health outcomes for different socioeconomic groups. In this perspective, income and education are predisposing factors. In the context of the present study, health literacy is implicated in the patient and their family’s ability to navigate the healthcare system and act as advocates for the patient. To be a successful patient advocate, the family needs to have a good understanding of what is required for the sick individual to successfully live and be cared for at home, including their own roles and responsibilities, as well as the healthcare system’s roles and responsiblities.

3.2.2. Need characteristics.

The second component of the Andersen model is need characteristics. These are factors that influence the individual’s perceived or determined need for healthcare services. Comorbidity, which refers to the presence of multiple health conditions, contributes to the overall level of healthcare needs by increasing the complexity and severity of individuals' health issues. Individuals with comorbidities may be more complex to treat, and may require more comprehensive and specialized care. The individual themselves may want more healthcare, and the healthcare professional may recommend more care as well. However, a competing hypothesis is that individuals with high comorbidity may have been sick for a longer period of time, and have therefore had more time to prepare, and thus be more likely to already be equipped with the necessary tools and resources to stay at home. One study found high CCI to be positively correlated with preparedness for EoL (29). Need factors may also be looked at on an aggregate level, including health indicators such as mortality and disability in the patient’s community. Although community-level factors were not considered in this study, they may help explain some of the remaining variance.

3.2.3. Predicposing characteristics.

The third and final component of Andersen’s model is enabling characteristics. Enabling characteristics include factors that make healthcare services more or less accessible. Selecting variables that are associated with enabling or hindering healthcare service use needs to consider the specific context the individual is in, including the barriers and facilitators that the individual is presented with in his or her healthcare system. As previously discussed, socioeconomic status may be considered a predisposing factor instead of an enabling factor in the Norwegian context, due to the high accessibility of healthcare services from a cost perspective. However, it is important to note that direct medical costs are not the only impeding factor. In rural areas, costs related to travel and inaccessibility due to distance may be important barriers to consider (21).

3.2.4. Relating geography to the Andersen model

The primary aim of this study was to assess the impact of geographic factors on healthcare use. In line with Andersen's framework, geography was hypothesized to be strongly implicated in the accessibility of healthcare for several reasons, and considered an enabling or impeding characteristic. First, urban-rural disparities in cancer outcomes are well documented (30, 31). Living in rural communities has been shown to be negatively associated with time at home at EoL in cancer (24). The urban-rural distinction was therefore important to capture in order to assess geographic variation in the outcome variables. It should be noted that Norway does not have an official definition of rural vs. urban communities in terms of population size cutoffs. Instead, this variable was defined by finding the quintiles of population size for all 356 municipalities, then assigning each individual to their respective quintile. However, in the case of Norway, the urban-rubal distinction was not sufficient to capture the entire geographic variations in the data. We also need to consider the geographic structure of Norway's administrative divisons.

Each region in Norway consists of many municipalities with broad-ranging population sizes. Consider two hypothetical individuals from two different municipalities with the same number of inhabitants; one lives in a geographically small municipality near the capital city Oslo, and another lives in a geographically large rural community in Northern Norway. It seems unlikely that the accessibility of healthcare services would be equal for the two individuals, dispite the fact that they match on the rural-urban variable. To account for this, two additional variables were included to reflect geographic location: distance to the nearest hospital in kilometers from the municipality center, and county (fylke) of residence. When investigating the effect of geography on healthcare use, we also have to consider the heterogeneity within regions and municipalities. Age and sex are likely not equally distributed across different levels of the urban-rural variable, as women and younger people are more likely to live in urban communities, among other reasons. Other discrepancies across sociodemographic variables may also exist. For example, some regions, although remote, may have a high density of high-income individuals due to industry. To account for such variations, it was important to adjust the model to account for sociodemographic factors in order to isolate the effect of the geography.

3.3. Regression analyses: model selection and specification

To select the model for the outcome variables, the Akaike Information Criterion (AIC) and Bayesian Information Criterion (BIC) were used to compare models. These are statistical measures used to choose the most appropriate model for a dataset, depending on the properties of the dataset. AIC measures the tradeoff between the goodness of fit of a model and its complexity. It takes into account the model's likelihood (how well it fits the data) and the number of parameters it uses. A lower AIC value indicates a better balance between fit and complexity, indicating the preferable model. BIC is similar to AIC, in that it also considers the likelihood and number of parameters. The penalty term in BIC is more severe, resulting in a more conservative approach to model selection. Like AIC, a lower BIC value suggests a better model.

A two-part model with logistic regression in the first part and ordinary least squares (OLS) regression in the second part were selected for the outcome variables. This model is particularly useful when dealing with data that exhibit a skewed distribution or contain a substantial number of zeros, as this modeling approach commonly used to analyze data with a two-step process. In this modeling framework, the two-part model accounts for two distinct aspects of the data: the probability of an event occurring (such as the presence or absence of a particular outcome) and the magnitude or level of the outcome when it is present. The logistic regression component models the probability of observing a zero outcome, while the OLS regression component models the level of the outcome when it is non-zero

The first part of the model utilized logistic regression, which is suitable for modeling binary outcomes or events with a probability ranging between 0 and 1. Logistic regression estimates the probability of an event occurring, given a set of predictor variables. It provides coefficients that represent the effects of these predictors on the likelihood of the event happening. The logistic regression component provides odds ratios or log odds, which represent the proportional change in the odds of the event occurring for a unit change in the predictor. The logistic regression model estimates the log odds (logit) of the event occurrence, allowing for the interpretation of the effects of predictors on the probability of the event. The second part of the model employed ordinary least squares (OLS) regression, which is often used for modeling continuous outcomes. In the second part, the model focuses on the subset of observations where the outcome variable is non-zero. OLS regression estimates the relationship between the continuous outcome variable and a set of predictor variables by minimizing the sum of squared residuals. The coefficients derived from the OLS regression represent the average change in the outcome variable associated with a unit change in the predictor variables. The OLS regression component provides coefficients that indicate the average change in the outcome variable associated with a unit change in the predictors.

3.4 Data preparation and variable groupings

Registry datasets were combined and linked by patient ID-number. All calendar dates had already been transformed from specific dates into a difference in days from an unknown reference date, as an additional step to anonymise the data. For patient contacts with the specialist healthcare services, data preparation required finding the day the individual was admitted to hospital, and the day they were discharged, and summarizing all days in hospital per month for each ID number. This was obtained from NPR. KPR contains in-depth information about municipal care services utilization. The registry contains information about the date the patient applied for each service, as well as date of decision, start-dates and end-dates. Only admission and discharge dates to municipal care institutions were relevant to the objectives of this study.

Decisions had to be made about what constitutes «at home», «short term care» and «long term care». KPR contains information regarding 25 types of services that relate to health and care, nine of which related to care in a municipal institution. These include (1) *Avlastning i institusjon* (support in an institution); (2) *Dagopphold i institusjon* (daytime stay in an institution); (3) *Tidsbegrenset opphold – utredning/behandling* (time limited stay for examination/treatment purposes); (4) *Tidsbegrenset opphold – habilitering/rehabilitering* (time limited stay for habilitation/rehabilitation purposes); (5) *tidsbegrenset opphold – annet* (time limited stay – other); (6) *Langtidsopphold i institusjon* (long-term stay in an institution); (7) *Nattopphold i institusjon* (overnight stay in an institution); (8) *Kommunal øyeblikkelig hjelp – døgnopphold* (municipal urgent care – 24 hour stay); (9) *Bolig som kommunen disponerer for helse- og omsorgsformål* (residence used by the municipality for healthcare purposes). Sub-24 hour stays, including daytime and nighttime only admissions, were excluded, as the individuals were not considered to be gone from home for a full 24 hours (1 day). There was some initial uncertainty regarding the classification of number nine, residence used by the municipality for healthcare purposes (omsorgsbolig). Although individuals living in such residences have more normalcy and daily automony compared to individuals living in nursing homes, these residences are designed for individuals to receive healthcare services, and typically have staff working there to assist the dwellers. This was therefore included in long-term stay.

Grouping decisions were made for sociodemographic variables. As previously discussed in section 3.2.1., being married/having a registered partner, and previous marriage or partnership, have been shown to be associated with more time at home at EoL. These were therefore grouped separately, to assess the effect independently. Previously married included being separated, divorced, and widowed. Those who had never been married were grouped separately. The age variable was categorized from a continuous variable to assess the incremental effect of age. It was hypothesized that age did not have linear relationship with time at home, but rather, that a much greater difference would be seen in very high ages (>80) compared to lower ages (<80). Those aged <50 were grouped together due to the small number of individuals in this group. Lastly, income was grouped according to 200 000 NOK increments to assess the incremental effect of income on days at home. High incomes in the >95% percentile were included in a separate category (>800 000 NOK/year) to account for very high earners and the potential difference in time at home and in hospital.

References

1. Statistisk sentralbyrå. Nasjonale befolkningsframskrivinger 2022 [Available from: https://www.ssb.no/befolkning/befolkningsframskrivinger/statistikk/nasjonale-befolkningsframskrivinger.

2. Ånen R, Sagan A, Saunes IS, Lindahl AK. Det norske helsesystemet. Health Systems in Transition. 2013;15.

3. Statistisk sentralbyrå. Helseregnskap 2022 [Available from: https://www.ssb.no/nasjonalregnskap-og-konjunkturer/nasjonalregnskap/statistikk/helseregnskap.

4. Oslo Economics. Arbeid, helse og kreft: OE-rapport 2022-81. 2022 2. November 2022.

5. World Health Organization. Cancer 2023 [Available from: https://www.who.int/health-topics/cancer#tab=tab_1.

6. Organization WH. International Statistical Classification of Diseases and Related Health Problems (ICD) [Available from: https://www.who.int/standards/classifications/classification-of-diseases.

7. Raknes G. Tall fra Dødsårsaksregisteret 2021: Folkehelseinstituttet; 2022 [Available from: https://www.fhi.no/hn/helseregistre-og-registre/dodsarsaksregisteret/tall-fra-dodsarsaksregisteret-2021/.

8. Cancer Registry of Norway. Cancer in Norway - Cancer incidence, mortality, survival and prevalence in Norway. Oslo, Norway; 2022.

9. Helsedirektoratet. Om pakkeforløpet 2022 [Available from: https://www.helsedirektoratet.no/nasjonale-forlop/hjem-for-pasienter-med-kreft/om-pakkeforlopet.

10. Helsedirektoratet. Lindrende behandling i livets sluttfase 2018 [Available from: https://www.helsedirektoratet.no/faglige-rad/lindrende-behandling-i-livets-sluttfase.

11. Bjørnelv G, Hagen TP, Forma L, Aas E. Care pathways at end-of-life for cancer decedents: registry based analyses of the living situation, healthcare utilization and costs for all cancer decedents in Norway in 2009-2013 during their last 6 months of life. BMC Health Services Research. 2022;22(1):1221.

12. Andersen SK, Croxford R, Earle CC, Singh S, Cheung MC. Days at home in the last 6 months of life: A patient-determined quality indicator for cancer care. Journal of oncology practice. 2019;15(4):e308-e15.

13. Barbera L, Paszat L, Charter C. Indicators of poor quality end-of-life cancer care in Ontario. Journal of palliative care. 2006;22(1):12-7.

14. Gyawali B, Niraula S. Cancer treatment in the last 6 months of life: when inaction can outperform action. ecancermedicalscience. 2018;12.

15. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC palliative care. 2013;12(1):1-13.

16. Sayer C. “Time spent at home”—a patient-defined outcome. NEJM Catalyst. 2016;2(2).

17. Foreman LM, Hunt RW, Luke CG, Roder DM. Factors predictive of preferred place of death in the general population of South Australia. Palliative medicine. 2006;20(4):447-53.

18. Nordsveen M, Larsen MH. Faktorer som påvirker kreftpasientens muligheter for å dø hjemme-en systematisk oversiktsartikkel. Inspira. 2022;17(1).

19. Helse- og omsorgsdepartementet. Meld. St. 24 (2019–2020). Lindrende behandling og omsorg.

20. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? Journal of health and social behavior. 1995:1-10.

21. Chen C, Gu D. Andersen Model. Encyclopedia of Gerontology and Population Aging: Springer; 2022. p. 433-48.

22. Franck J-e, Ringa V, Coeuret-Pellicer M, Chauvin P, Menvielle G. The determinants of cervical cancer screening uptake in women with obesity: application of the Andersen's behavioral model to the CONSTANCES survey. Cancer Causes & Control. 2020;31:51-62.

23. Lee Y-S, Roh S, Moon H, Lee KH, McKinley C, LaPlante K. Andersen's behavioral model to identify correlates of breast cancer screening behaviors among Indigenous women. Journal of Evidence-Based Social Work. 2020;17(1):117-35.

24. Cohen J, Houttekier D, Onwuteaka-Philipsen B, Miccinesi G, Addington-Hall J, Kaasa S, et al. Which patients with cancer die at home? A study of six European countries using death certificate data. J Clin Oncol. 2010;28(13):2267-73.

25. Devik SA, Hellzèn O. Palliasjon i rurale strøk: lindrende omsorg for eldre kreftpasienter som bor hjemme. En systematisk litteraturstudie. 2013.

26. Bjørnelv GMW, Edwin B, Fretland ÅA, Deb P, Aas E. Till death do us part: the effect of marital status on healthcare utilization and costs at end-of-life. A register study on all colorectal cancer decedents in Norway between 2009 and 2013. BMC health services research. 2020;20(1):1-13.

27. Higginson IJ, Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. Journal of palliative medicine. 2000;3(3):287-300.

28. Sorensen K, Van der Broucke S, Fullam J. Health literacy and public health: a systematic review and integration of definitions and models. bmc Public Health, 12, 80.

29. Wentlandt K, Burman D, Swami N, Hales S, Rydall A, Rodin G, et al. Preparation for the end of life in patients with advanced cancer and association with communication with professional caregivers. Psycho-Oncology. 2012;21(8):868-76.

30. Lewis-Thames MW, Langston ME, Khan S, Han Y, Fuzzell L, Xu S, et al. Racial and ethnic differences in rural-urban trends in 5-year survival of patients with lung, prostate, breast, and colorectal cancers: 1975-2011 Surveillance, Epidemiology, and End Results (SEER). JAMA network open. 2022;5(5):e2212246-e.

31. Zahnd WE, James AS, Jenkins WD, Izadi SR, Fogleman AJ, Steward DE, et al. Rural–urban differences in cancer incidence and trends in the United States. Cancer Epidemiology, Biomarkers & Prevention. 2018;27(11):1265-74.

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst A	Tove Irene Klokk	22845522	12.12.2022	170128

Tron Anders Moger

Dispensasjon fra taushetsplikt annen forskning: NORCHER - Norsk senter for helsetjenesteforskning
Søknadsnummer: 170128
Forskningsansvarlig institusjon: Universitetet i Oslo
Samarbeidende forskningsansvarlige institusjoner: Stiftelsen Frischsenteret for samfunnsøkonomisk forskning

Dispensasjon fra taushetsplikt annen forskning: Endring godkjennes

Søkers beskrivelse

Det er flere utfordringer som vil treffe alle nivåer av helsevesenet i nær fremtid: Befolkningen blir stadig eldre, man får et økende antall multisyke, og man får kanskje høyere forventninger til omsorgen som tilbys. Dette vil medføre større belastning på helsevesenet som helhet, men presset blir kanskje særlig stort innen kommunehelsetjenesten. Hvilke personer risikerer å bli omsorgsintensive i fremtiden, hvor tidlig kan de identifiseres og hva er helsetjenesteforbruket og kostnader forbundet med disse personene? Er det viktige ulikheter i tilgang til og kvaliteten på omsorgen som skyldes geografiske, individuelle og familiemessige faktorer? Hvordan kan man fange opp pasienter i kommunehelsetjenesten som senere har høy risiko for uførhet og lav tilknytning til arbeidslivet på et tidlig stadium, og finnes det måter å organisere tjenestene på som reduserer risikoen for å falle utenfor? Hva er fellestrekkene og ulikhetene mellom nordiske land, og kan denne kunnskapen brukes til å utvikle ytterligere hypoteser om hvordan tjenestene bør organiseres? Prosjektet som kalles NORCHER - Norsk senter for helsetjenesteforskning - er etablert for å møte disse utfordringene. Prosjektet drives av ved Avdeling for helseledelse og helseøkonomi ved UiO og er finansiert av Norges Forskningsråd. Da problemstillingene er komplekse og ikke begrenset til spesifikke diagnoser, krever de kobling av data fra flere kilder for å etablere informasjon om komplette pasientforløp, samt sosiodemografiske og –økonomiske variabler på individnivå fra sentrale populasjonsbaserte registre med lang oppfølgingstid.

Vi viser til søknader om endring i dispensasjon fra taushetsplikt annen forskning datert 30.11.2022 og 07.12.2022 for ovennevnte prosjekt.

Vurderingen av om det kan gis dispensasjon fra taushetsplikt for tilgjengeliggjøring og bruk av helseopplysninger ved gjennomføringen av prosjektet er gjort med hjemmel i helseregisterloven § 19 e, første ledd, jf. forskrift av 27. mai 2021 nr. 1725 om overføring av myndighet til den regionale komiteen for medisinsk og helsefaglig forskningsetikk (REK).

REKs vurdering

Det søkes om å inkludere fire nye medarbeidere i prosjektet:

- Nora Østbø, Universitetet i Oslo.
- Ann-Christin Grauer, Universitetet i Oslo.
- Anne Aasen Godøy, Universitetet i Oslo.
- Elina Aas, Universitetet i Oslo.

Det er vedlagt oppdatert liste over alle prosjektmedarbeidere.

Sekretariatet har vurdert endringene og har ingen innvendinger mot at disse gjennomføres som beskrevet.

Vedtak

Med hjemmel i helseregisterloven § 19 e, første ledd, godkjenner REK sør-øst A tilgjengeliggjøring og bruk av helseopplysninger i gjennomføringen av forskningsprosjektet uten hinder av taushetsplikten etter helseregisterloven § 17.

Dispensasjonen fra taushetsplikt gjelder til 31.12.2030.

Sluttmelding

Prosjektleder skal sende sluttmelding til REK på eget skjema via REK-portalen senest 6 måneder etter sluttdato 31.12.2030, jf. helseforskningsloven § 12. Dersom prosjektet ikke starter opp eller gjennomføres meldes dette også via skjemaet for sluttmelding.

Søknad om endring

Dersom man ønsker å foreta vesentlige endringer i formål, metode, tidsløp eller organisering må prosjektleder sende søknad om endring via portalen på eget skjema til REK, jf. helseforskningsloven § 11.

Klageadgang

Du kan klage på REKs vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes på eget skjema via REK portalen. Klagefristen er tre uker fra du mottar dette brevet. Dersom REK opprettholder vedtaket, sender REK klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering, jf. forskningsetikkloven § 10 og helseforskningsloven § 10.

Vennlig hilsen

Jacob C. Hølen
Sekretariatsleder
REK sør-øst

Tove Irene Klokk
Seniorrådgiver
REK sør-øst

Kopi til:

Universitetet i Oslo
Stiftelsen Frischsenteret for samfunnsøkonomisk forskning
Terje Per Hagen