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Geographical Differences in Likelihood of Home Death Among Palliative Cancer Patients: A National Population-based Register Study

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Abstract. *Background/Aim: Previous studies have shown discrepancies between patient's desired and actual death place. As planning of family support and involvement of palliative home care teams seem to improve the chance to meet patients preferences, geographical availability of specialized palliative home care could influence place of death. Patients and Methods: Data of patients diagnosed and deceased between January 2011 until December 2014 with lung, brain, colorectal, breast and prostate cancer was collected from Swedish national registers and multiple regression analyses were performed. Results: Patients with lung, brain, colorectal, and prostate cancer who resided in rural municipalities had a higher likelihood of dying at home than dying in hospital settings, compared to those who lived in urban areas. Conclusion: Patients in Sweden, with the exception of breast cancer patients, have a higher likelihood of home death than inpatient hospital death when residing in rural areas compared to when residing in urban areas.*

An important issue in palliative care is the individual patient's choice of place of death (1). Previously, it has been suggested that most people prefer to die at home (2); however, it is important to keep in mind that some patients prefer other locations (1). This suggests discrepancies between patients' preferred and actual place of death (1-3). It is important to identify patients' wishes and to plan end-of-life care accordingly, since factors such as physician support, family support, hospice enrollment, and family caregiving ability seem to improve the chances of meeting patients' preferences for place of death (3, 4). As cancer patients are frequently admitted to hospitals due to acute conditions or refractory symptoms (5), there is a possibility that inadequate home treatment may lead to extra hospital admissions and potentially a higher proportion of patients that die on a ward. Also, there is a broad spectrum of symptomatology that differs across different cancer diagnoses (6, 7); having a specific cancer could possibly predispose an individual to inpatient death.

Another explanation for undesirable inpatient hospital deaths could be geographical distance to specialized care, since availability of a palliative home-care team (PHCT) seems to reduce hospitalization and inpatient hospital deaths (8).

The aim of the present study was to investigate if residency (rural versus urban) for cancer patients that have received palliative care and are included in the Swedish Register of Palliative Care (SPRC) is associated with a patient's likelihood of dying at home compared to dying in hospital settings.

Patients and Methods

Swedish register of palliative care. SRPC is a national quality register established in 2005 with the purpose to improve the quality of palliative care provided during the last week of life in Sweden. Data is collected through a structured web questionnaire that comprises thirty questions of interest to palliative care. The survey covers the last week of life of the deceased and is answered retrospectively by involved health professionals (nurses or physicians). The validity of the questionnaire has been studied (9, 10), and a revised version with improved validity was published in 2011.

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Data collection. Data was obtained from the SRPC involving patients recorded from January 1, 2007 through June 22, 2015. However, due to a revision of SRPC in 2011, patient data between 2007 through 2010 was excluded. By using personal identity numbers assigned to all Swedish permanent citizens at birth, records were linked between SRPC and the Swedish Cancer Register (SCR) (11) to extract patients with lung cancer (ICD, International Classification of disease, C34), high-grade brain tumors (C71), prostate cancer (C61), breast cancer (C50), and colorectal cancer (C18, C19 & C20). Breast, colorectal, lung, and prostate cancer are the most common diagnosed malignancies in Sweden and were therefore chosen. High-grade brain tumors were included because these patients are often referred to palliative care units and are often admitted to hospital care due to the diversity of symptoms that these patients often are presented with. Further, the inclusion criteria for the patients stipulated that patients had to have been both diagnosed and deceased due to cancer during 2011 through 2014. Patients who survived more than four years after diagnoses or were diagnosed prior to 2011 were excluded from the present study.

Information on underlying cause of death and place of death was obtained from the Cause of Death Register (CDR) (12), coded in accordance with the ICD system. Data from SCR and CDR extended from January 2011 through December 2014. To enable record linkage involving all subjects, patient data after December 31, 2014 was excluded. ICD version 10 was used.

Definitions of urban and rural areas. An urban area was defined in accordance to SKL's (Swedish Association of Local Authorities and Regions) definition of populated areas. This definition includes all municipalities defined as large cities (more than 200,000 inhabitants within the largest urban area in the municipality) and commuting municipalities near large cities (more than 40% of the inhabitants commute to work in a large city or municipality near a large city). Other urban municipalities include medium-sized towns (at least 50,000 inhabitants with 40,000 or more inhabitants in the largest urban area within the municipality), commuting municipalities near medium-sized towns (more than 40% of the inhabitants commute to a medium-sized town), and commuting municipalities with a low commuting rate near a medium-sized town (less than 40% of the inhabitants commute to a medium-sized town). All other municipalities were defined as rural areas. A total of 153 rural and 137 urban areas were defined according to SKL's definitions. Urban or rural residency of each patient was determined according to the registered residence municipality at time of death (13).

Study population. All patients with lung, breast, colorectal, prostate, and brain cancer who were diagnosed and died due to malignancy from 2011 through 2014 and registered in the SRPC were included in the study.

Statistical analysis. We used multiple logistic regressions to assess the relationship between residency and whether patients died at home or at a hospital. Our dependent binary variable equaled 1 if the individual had died at home and 0 if he or she died at a hospital. Our primary independent variable of interest was whether patients lived in a rural or urban municipality at the time death occurred. We also included two possible confounder variables: age and sex. Adjusted odds ratios (aOR) and corresponding 95% confidence intervals (CI) were used as inference for all variables in the models, interquartile-range odds ratios for age and simple odds ratios for residency and sex. The function ANOVA from the R package rms (14) was used for testing the assumptions of linearity in age, and for searching possible interaction effects. For descriptive statistics, age is presented as median, first and third quartile (Q1, Q3), min and max; residence and sex are presented as frequency and proportion (%). Data processing and statistical analysis were performed with the statistical software R by R Core Team (2017). R: A Language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria.(15).

Results

A total of 130,785 registrations from January 1, 2007 through June 22, 2015 were retrieved from SRPC. After exclusion of registrations that did not meet the inclusion criteria, 8,990 patients from January 1, 2011 through December 2014 were included in the study (Figure 1). Using SKL definitions, we identified 153 urban and 137 rural municipalities (Figure 2).

Study characteristics. Among the diagnoses included, lung cancer was the most common followed by colorectal cancer, prostate cancer, breast cancer, and brain cancer (Table I).

Place of death. Patients with lung, brain, colorectal, and prostate cancer residing in rural municipalities all had a higher likelihood of dying at home than dying in a hospital, compared to those who lived in urban areas, holding age and sex constant. We were unable to find any such difference in patients with breast cancer (Tables II and III).

Discussion

In the present study, 8,990 cancer patients were identified from the first of January 2011 through December 2014, and these patients were identified as living in 153 urban and 137 rural municipalities. The present study shows that amongst these palliative cancer patients, patients with lung, brain, colorectal, and prostate cancer residing in rural areas were associated with a higher likelihood of dying at home than in hospital settings compared to those residing in urban areas. However, we were unable to identify such a pattern among patients with breast cancer.

In a previous study by Öhlen *et al*. (16), the authors investigated all cancer deaths in Sweden during a single year (2012) and found that living in urban areas was associated with a higher likelihood of dying in hospital, thus confirming the findings of the present study.

How can these findings be explained? Initially, symptoms such as pain, respiratory distress, and gastrointestinal problems (which all are common symptoms for cancer patients) are likely to lead to hospital visits and admittance (5). However, patients in rural as well as in urban areas have

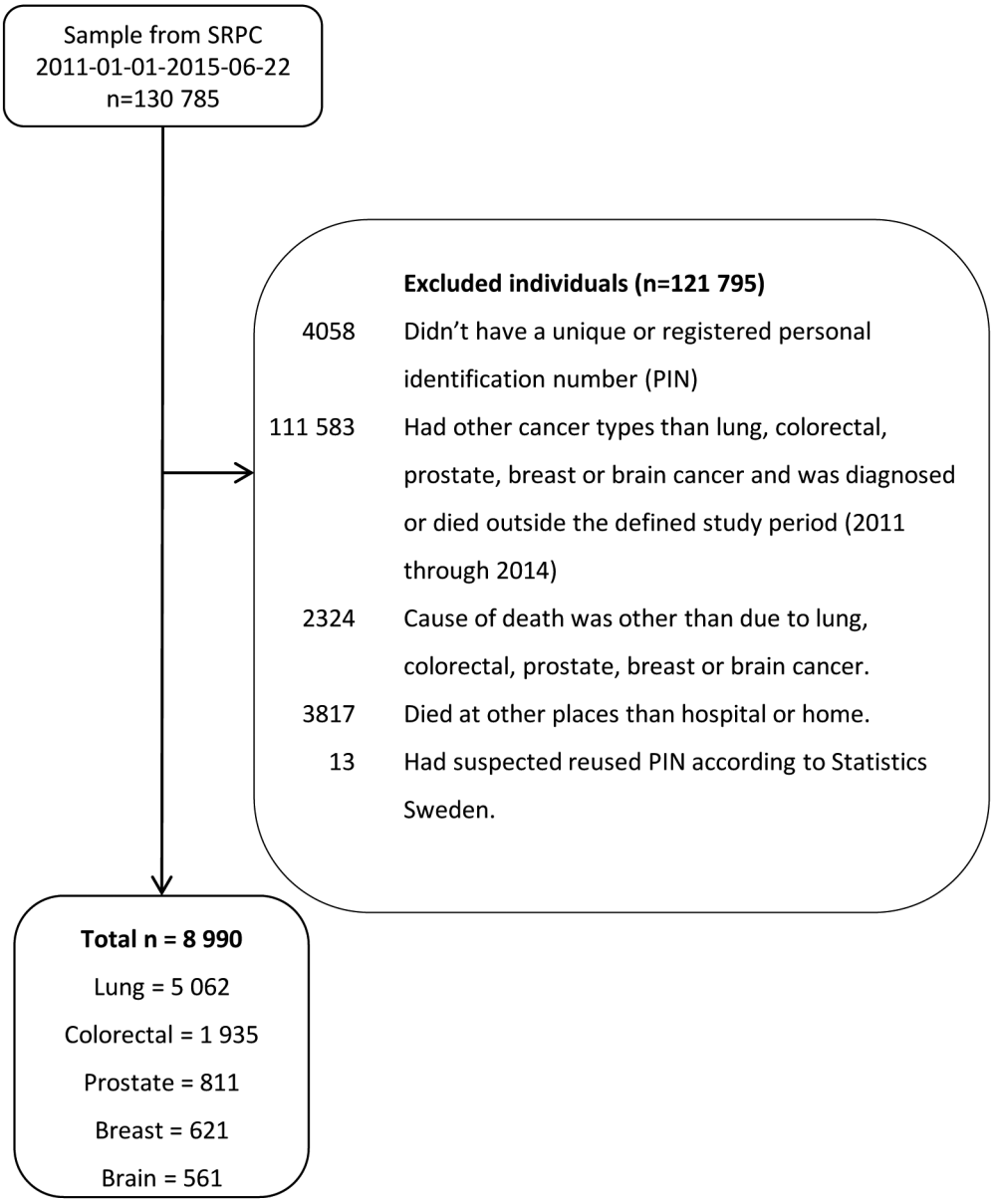

Figure 1. *Patient flow chart*.

the same symptoms, so other factors must be sought. One of these could be the distance to the hospital, and data have shown that having a hospital within a limited distance from your home increases the likelihood of hospital visits (17). Further, if the geographical distance to hospital settings increases, this might impair visits by relatives and loved ones, which might be an issue for patients living in a rural area, diminishing their desire to be admitted to hospitals and increasing their wish to continue to be taken care of by specialized home-care teams.

At the same time, according to the literature, one of the most thoroughly investigated factors for determining the place of death among cancer patients has been the individual patient's socioeconomic standards (3). A Canadian retrospective cross-sectional study by Raziee *et al*. (18) showed an association between home death and high economic standard in urban areas and a lower chance of home death in rural areas, which contradicts our results. Similar results were seen in an Australian study of 1582 cancer patients in which patients living in more affluent metropolitan suburbs were more likely

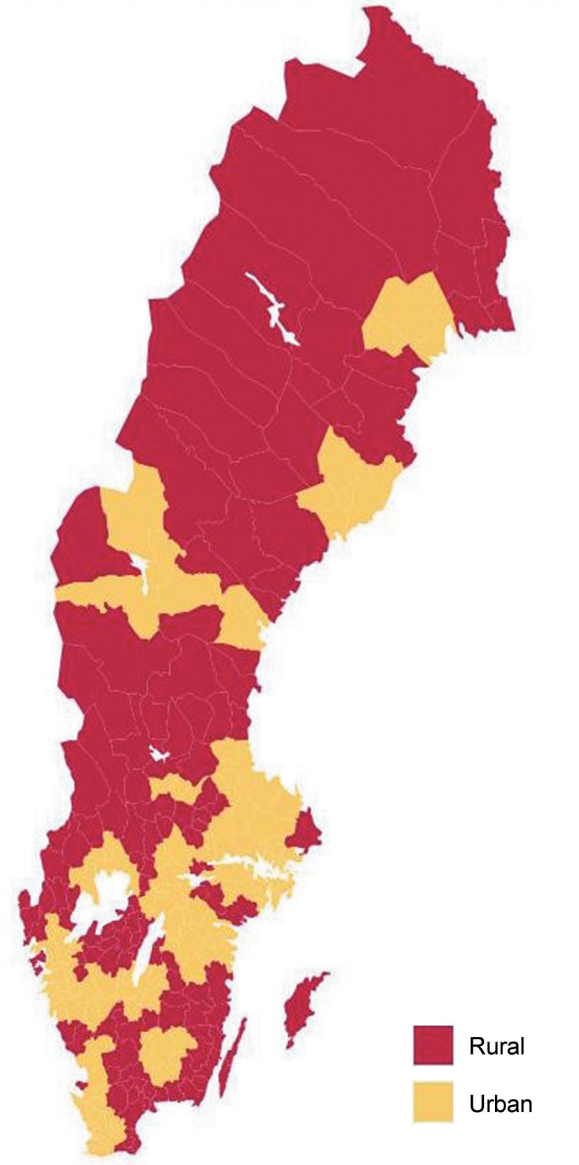

Figure 2. *One hundred and thirty-seven urban and 153 rural municipalities according to Swedish association of local authorities and regions definitions.*

Table I. *Descriptive characteristics of study population by diagnosis.*

	Total	Home	Hospital
Brain (n=561)			
Age			
Median (IQR)	65 (56-72)	65 (54-72.5)	65 (57-72)
Min-Max	0-89	5-89	0-89
Gender			
Female	207 (100%)	92 (44.4%)	115 (55.6%)
Male	354 (100%)	147 (41.5%)	207 (58.5%)
Residence			
Rural	124 (100%)	63 (50.8%)	61 (49.2%)
Urban	437 (100%)	176 (40.3%)	261 (59.7%)
Breast (n=621)			
Age			
Median (IQR)	69 (58-80)	66 (58-78.75)	69 (58-81)
Min-Max	27-100	33-94	27-100
Gender			
Female	619 (100%)	174 (28.1%)	445 (71.9%)
Male	2 (100%)	0 (0%)	2 (100%)
Residence			
Rural	143 (100%)	46 (32.2%)	97 (67.8%)
Urban	478 (100%)	128 (26.8%)	350 (73.2%)
Colorectal (n=1935)			
Age			
Median (IQR)	74 (66-81)	73 (65-81)	74 (66-81)
Min-Max	15-99	22-97	15-99
Gender			
Female	927 (100%)	307 (33.1%)	620 (66.9%)
Male	1008 (100%)	395 (39.2%)	613 (60.8%)
Residence			
Rural	498 (100%)	230 (46.2%)	268 (53.8%)
Urban	1437 (100%)	472 (32.8%)	965 (67.2%)
Lung (n=5062)			
Age			
Median (IQR)	71 (65-78)	72 (66-79)	71 (65-77)
Min-Max	14-97	14-95	23-97
Gender			
Female	2391 (100%)	517 (21.6%)	1874 (78.4%)
Male	2671 (100%)	595 (22.3%)	2076 (77.7%)
Residence			
Rural	1283 (100%)	316 (24.6%)	967 (75.4%)
Urban	3779 (100%)	796 (21.1%)	2983 (78.9%)
Prostate (n=811)			
Age			
Median (IQR)	76 (69-82.5)	77 (70-83)	76 (69-82)
Min-Max	48-97	48-95	49-97
Gender			
Male	811 (100%)	295 (36.4%)	516 (63.6%)
Residence			
Rural	226 (100%)	102 (45.1%)	124 (54.9%)
Urban	585 (100%)	193 (33%)	392 (67%)

IQR: Interquartile range.

to die at a private residence than were those from poorer suburbs or rural areas, who were more likely to die at an institution (19). Also, in a study from Nova Scotia, Canada, rural residents had a lower likelihood of home death than patients living in urban areas (20). However, the availability of palliative home-care treatment (PHCT) may differ between Sweden and geographically large countries with low population density such as Canada and Australia.

When it comes to decisions concerning whether patients want to die at home or in an institution/hospital, different explanations exist. One of these factors can be where the patient actually lives. In a German study, patients living in a rural municipality had a higher association with dying at home than dying at an institution (21). This accords with the

Table II. *Place of death in urban or rural regions, by diagnosis.*

	Adjusted odds ratios (95%CI)	*p*-Value
Brain (n=561)		
Age		
Q1	ref	
Q3	0.91 (0.75-1.09)	0.30
Gender		
Male	ref	
Female	1.14 (0.8-1.61)	0.48
Residence		
Urban	ref	
Rural	1.54 (1.03-2.3)	0.035
Breast (n=621)		
Age		
Q1	ref	
Q3	0.86 (0.67-1.1)	0.23
Residence		
Urban	ref	
Rural	1.31 (0.87-1.97)	0.19
Colorectal (n=1935)		
Age		
Q1	ref	
Q3	0.88 (0.77-1)	0.051
Gender		
Male	ref	
Female	0.78 (0.64-0.94)	0.008
Residence		
Urban	ref	
Rural	1.77 (1.43-2.18)	<0.0001
Lung (n=5062)		
Age		
Q1	ref	
Q3	1.14 (1.04-1.24)	0.004
Gender		
Male	ref	
Female	0.97 (0.85-1.11)	0.70
Residence		
Urban	ref	
Rural	1.23 (1.06-1.43)	0.007
Prostate (n=811)		
Age		
Q1	ref	
Q3	1.08 (0.88-1.33)	0.46
Residence		
Urban	ref	
Rural	1.67 (1.22-2.29)	0.001

Q1: First quartile; Q3: third quartile. An odds ratio greater than 1 implies a higher likelihood of home death and less than 1 implies a higher likelihood of in hospital deaths.

Table III. *Distribution of place of death by diagnosis.*

	Total	Home	Hospital
Brain	561 (100%)	239 (42.6%)	322 (57.4%)
Breast	621 (100%)	174 (28%)	447 (72%)
Colorectal	1935 (100%)	702 (36.3%)	1233 (63.7%)
Lung	5062 (100%)	1112 (22%)	3950 (78%)
Prostate	811 (100%)	295 (36.4%)	516 (63.6%)

present study. Similar results were seen in a study from Belgium, where living in rural municipalities had the highest likelihood of dying at home (22). Also, in studies from the United States (23), Italy (24), and Spain (25), rural environments were associated with a higher likelihood of dying at home. In one recent study from the United States, patients living in rural areas had the highest rate of home death as compared with patients living in urbanized areas, although the difference was not statistically significant (26). The factors that influence place of death for terminally ill patients have been reviewed in a large meta-analysis of 58 studies from 13 countries that included over 1.5 million patients (27). It concluded that a higher likelihood of dying at home was reported for rural areas.

The present study is a register-based study, with data from SRPC, which has high validity and covers a majority of patients who died of cancer (9). In the present study, the number of breast cancer deaths was 621. However during the study period, the number of breast cancer deaths according to the Swedish Cause of Death Register (SCDR) was 5,772 (28). Further, the number of patients dying of prostate cancer during the study period is 811 patients in the present study whereas the total number of prostate cancer deaths according to SCDR is 9,525 patients during the study period (28). A possible explanation could be a lower registration rate to SRPC among these patients, which hypothetically could reflect a lower rate of inclusion in advanced palliative care compared to other diagnoses. However, since the inclusion covers patients that were both diagnosed with and died of cancer during the period 2011 through 2014, patients who survived more than four years after diagnoses, or were diagnosed prior to 2011 were therefore not included in the present study. Since the relative 5-year survival of breast cancer is about 90% (but decreases drastically in late-stage disease) (29, 30) and as the relative 5-year survival rate for prostate cancer patients is similar (29, 31, 32), this could explain the relatively low percentage of patients with breast and prostate cancer patients in the present study.

The findings of this study are important, since awareness of potential factors that influence place of death is crucial for improving the quality of end-of-life care. There have been several previous studies in this field. However, our study is nationwide, register-based, and the first in a series of studies designed to investigate the issue.

In conclusion, data from the present study suggests that late-stage palliative cancer patients in Sweden registered in SRPC have a higher likelihood of dying at home than at a hospital setting when residing in rural areas compared to

patients residing in urban areas, although this is a finding that was not observed in breast cancer patients. More studies are warranted to examine whether the discrepancy reflects place-of-death preferences of the patients or whether it is due to differences in health-care availability and consumption.

Conflicts of Interest

The study was approved by the regional ethics committee of Uppsala. All data are based on deceased persons. However, the dataset does include multiple variables, thus potentially making identification a concern. The dataset will therefore not be published. The Authors report no conflicts of interest in relation to this study.

Authors' Contributions

Jonas Nilsson, Tobias Carlsson, Michael Bergqvist and Stefan Bergström have contributed to study design and data withdrawal. Tobias Carlsson performed the statistical processing. All Authors helped with the interpretation of the results. Jonas Nilsson and Georg Holgersson have contributed to manuscript processing. All Authors have revised the manuscript.

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