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Equal palliative care for foreign-born patients: A national quality register study

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Original Article

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Abstract

Objectives. To use data from a national quality register to investigate if there are differences relating to migrant background in the quality of end-of-life care of patients dying in Sweden.
Methods. A retrospective, comparative register-based study. In total, 81,418 deceased patients, over 18 years of age, registered in the Swedish Register of Palliative Care during 2017 and 2018, of expected death were included in the study. Of these, 72,012 were Swedish-born and 9,395 were foreign-born. Descriptive and analytical statistical methods were used.
Results. No general pattern of differences in quality regarding end-of-life care was found between Swedish- and foreign-born patients. There were several significant differences in various quality indicators but not in a specific direction. Sometimes, the quality indicators showed an advantage for Swedish-born patients but just as often, they were also favorable for foreign-born patients. Swedish-born patients had greater access to specialized palliative care than foreign-born patients. Foreign-born patients were more often cared for in general home care setting, despite a higher frequency of cancer diagnosis.
Significance of results. Foreign-born patients were less likely to be cared for in specialized palliative care units and had poorer access to palliative care teams than Swedish-born patients, despite having a higher proportion of cancer diagnoses. However, no general pattern was found indicating that foreign-born patients were disadvantaged in the quality indicators measured in the present study. Perhaps, this is an indication that the palliative care in Sweden is individualized; nonetheless, the quality of end-of-life care would be higher if dying patients, regardless of country of birth, have better access to specialized palliative care.

Introduction

In 2015, the number of migrants was the highest ever in Sweden, when nearly 163,000 individuals sought asylum (SCB Statistics Sweden, 2016). The newcomers mainly originated from Afghanistan, North Africa, and Syria. This was added to the migrant population already living in Sweden, who were labor migrants that mainly immigrated during the postwar era and the 1970s, from Finland and ex-Yugoslavia. From mid-1985, the pattern of immigration changed to mainly include refugees, with a first wave from Latin America, Asia, and Africa and another peak during the 1990s from the war in ex-Yugoslavia and the Middle East. Thus, the migrant population is a mix of nationalities (>140), and the number of foreign-born is about 20% of the population (10 million; Statistics Sweden, 2019).

Much of what is known about the current content and the quality of palliative care in Sweden is based on data from the Swedish Register of Palliative Care (SRPC) (Lundström et al., 2012). This registry contains individualized data concerning patient problems, medical interventions, and outcomes after treatment within all health care. During 2017 and 2018, 58,243 respective 55,855 deaths were reported to the SRPC, representing just over 60% of all deaths in that specific year in Sweden (The Swedish Register of Palliative Care, 2018). Studies on that data have showed that access to high-quality palliative care for people suffering from life-threatening and incurable diseases is unequal and differs in an unfair way depending on diagnosis (Brännström et al., 2011; Ahmadi et al., 2016; Eriksson et al., 2016), place of care (Henoch et al., 2019), and age (Lindskog et al., 2015). Palliative care, as delivered today, can also be unfair since it is not always based on individual needs. Moreover, people with migrant backgrounds risk not receiving the same quality and quantity of care as native Swedes, depending on different social and economic status, lack of knowledge regarding alternatives of end-of-life care, and communication difficulties. To the best of our knowledge, there are no previously published studies focusing on a variety of quality of care indicators in end-of-life care involving people with migrant backgrounds.

Studies from other countries, especially from UK and US, have investigated if ethnic status constitutes a risk for disparities in palliative care (Elkan et al., 2007; Cohen, 2008; Coupland et al., 2011; Evans et al., 2011; Johnson, 2013; Garrido et al., 2014; Worster et al., 2018). A register-based study on differences regarding place of death between ethnic groups showed significant differences between various ethnic groups and white patients (Coupland et al., 2011).

However, these results are not completely applicable and valid for Swedish conditions with our specific migration patterns and the heterogeneous migrant population. A recent study from Germany, with a more comparable immigration pattern as the Swedish, showed an unequal utilization of specialized palliative care by immigrants, especially those originating from Turkey (Henke et al., 2017). Still, what is unknown is if migrants, in need of palliative care, are more often cared for in their home with support from home care delivered by the primary health care and/or the municipality than in an institution, and if the care differs in other quality indicators compared with native Swedes. Using data from the national SRPC (Lundström et al., 2012) gives a unique opportunity to study whether care delivered was given on equal terms, and what kind of support has been given to individuals with migrant backgrounds compared with native Swedes.

The aim of this study is to use data from a national register to investigate if there are differences relating to migrant background when it comes to the quality of end-of-life care for patients dying in Sweden.

Method

Design

A retrospective, comparative study using data from the national quality register, the SRPC.

Sample

An extract of register data for all expected deaths (and do not know/missing, cases), for those over 18 years age, registered in the SRPC during 2017–2018, constitutes the study sample. A comparison of SRPC data with information from the Swedish Cause of Death Register allowed for separation according to country of birth.

Data collection and variables

Data were collected through an online end-of-life questionnaire (EOQ; Lundström et al., 2012), with items based on different essential aspects of end-of-life care in the last week of life. The questions, which are mandatory and have to be answered before submission, are answered by the responsible registered nurse and/or physician as soon as possible following the patient's death. Data for patients reported as cases of unexpected death were excluded in this study because they lack complete data as opposed to data on patients with expected deaths. From the EOQ, data on age, gender, place of death, and 16 questions with different quality of care process indicators were retrieved. For the most part, those questions could be answered with yes, no, and do not know. Data on country of birth and medical condition were obtained from the Swedish Cause of Death Register held by the Swedish National Board of Health and Welfare.

Data processing and statistical analysis

Descriptive statistics were calculated for the individual variables with means and SD for continuous variables, and frequencies and percentages for categorical data. Comparisons were made by conducting tests of statistical significance by chi-squared test or Fisher's exact test for categorical variables, and Students *t*-test or Mann–Whitney U-test when appropriate for continuous variables. The two items from the Swedish Cause of Death Register were processed in nine pre-defined categories for country of birth (see Supplementary Appendix 1), and the International Classification of Diseases codes (ICD-codes) were grouped into nine categories (see Table 1).

For each quality indicator, we tested whether or not its implementation in the end-of-life care could be predicted by the patient's country of birth (independent variable) using pre-defined categories. All data were dichotomized, and binary logistic regression analyses were used to calculate odds ratios (ORs) with 95% confidence intervals (CIs). The binary logistic regression analyses were theory-driven. In the first step, we entered country of birth into the model; next, we entered age and gender, followed by diagnosis. The last step in the regression analysis was to add the type of end-of-life care unit to the model. The Swedish-born patients were used as a reference group. A p-value of less than 0.05 was considered significant. Calculations were performed in SPSS version 25 (SPSS, Inc., Chicago, IL).

Ethics

The study was approved by the National Ethics Authority (EPN D-number 2019–02971). All collected data were anonymized and coded so that no specific individual might be identified. All patients were deceased, and it was not possible to obtain informed consent from the patients; however, as this was a quality register study, all patients had been informed in advance about the national quality registers, as well as about voluntary participation and confidentiality, as part of the health care routines. The SRPC management group approved the study.

Results

In total, 81,418 deceased patients, over 18 years of age, registered in the SRPC during 2017 and 2018 of expected death (or do not know/missing), were included in the study. The mean age in the study population was 82 (r 19–110) years, and it was significantly higher in Swedish-born patients compared with foreign-born, 82.5 versus 79 ($p = <0.001$).

Background data are described in Tables 1 and 2. Depending on place of death (Table 1), the Swedish-born group had been cared for in a nursing home (38.1% vs. 31.1%, $p = <0.001$), specialized in-patient palliative care (8.0% vs. 5.9%, $p = <0.001$), or in specialized palliative home care (4.5% vs. 4%, $p = <0.05$), to a higher extent than foreign-born patients. The foreign-born patient group was overrepresented in end-of-care units with short-term stay in nursing homes (18.1% vs. 12.4%, $p = <0.001$) and general home care (8.9% vs. 5.7%, $p = <0.001$), and in unspecified care, that is, a blended group, mostly consisting of intensive care units ($p = <0.05$).

When considering the five main groups of diagnoses, significant differences were found between Swedish- and foreign-born patients. Having a cancer diagnosis was more common in foreign-born than Swedish-born patients (38.6% vs. 33.3%, $p = <0.001$), while heart/circulation diseases (27.7% vs. 25.1%, $p = <0.001$), neurological diseases (7.2% vs. 6.3%, $p = <0.001$), and dementia/psychiatric diseases (9% vs. 8.3%, $p = <0.05$) were more prevalent in Swedish-born than foreign-born patients. No difference was found for respiratory diseases. The biggest migrant groups originated from Nordic countries as well as Slavic or Eastern European countries (Table 2).

Table 1. Background data of the patients reported to the SRPC during 2017–2018

	Swedish-born		Foreign-born		
	72.012		9.395		
Category	***n***	**%**	***n***	**%**	*p*-value
Sex					*0.01*
Male	32.560	*45*	4.000	*43*	
Female	39.452	*55*	5.212	*57*	
Diagnosis					
Cancer/hematology issues/immune disease	24.003	*33.3*	3.554	*38.6*	*0.000*
Circulation/heart disease	19.940	*27.7*	2.313	*25.1*	*0.000*
Dementia/psych	6.467	*9.0*	766	*8.3*	*0.05*
Respiratory disease	5.278	*7.3*	677	*7.3*	*NS*
Neurologic disease	5.165	*7.2*	585	*6.3*	*0.000*
Digestive disease	1.836	*2.5*	243	*2.6*	*NS*
Endocrine disease	1.812	*2.5*	264	*2.9*	*NS*
Infection	1.705	*2.4*	183	*2.0*	*0.05*
Other	7.511	*10.4*	841	*8.9*	*0.000*
Place of death					
Nursing home	27.411	38.1	2.868	31.1	*0.000*
Hospital	21.065	29.2	2.755	29.9	*NS*
Specialized palliative care, in-patient units	5.758	8.0	545	5.9	*0.000*
Short-term stay, nursing homes	8.913	12.4	1.666	18.1	*0.000*
General home care	4.107	5.7	824	8.9	*0.000*
Specialized palliative home care	3.259	4.5	365	4.0	*0.05*
Own home-daily home service	1.080	15.0	117	12.7	*NS*
Own home	34	0.04	4	0.04	*NS*
Other (unspecified place)	385	0.5	68	0.7	*0.05*

Table 3 shows descriptive data on quality indicators. The quality indicator that reached the highest levels in both Swedish- and foreign-born patients was the prescription of rescue medicines (84.2–94.1% vs. 83.9–94.0%). Likewise, the likelihood that the patients had received some kind of consultation services was lowest among the quality indicators, in both the Swedish- and foreign-born patients (0.8–7.8% respective 0.9–7.5%).

Prescribed rescue medicines and systematic assessment of end-of life symptoms

The pattern for end-of-life prescriptions of rescue medicines was inconsistent; for some indicators, the care was an advantage for the Swedish-born patients compared with the subgroups of the foreign-born patients, and for other indicators, the Swedish-born patients were disadvantaged (Tables 3 and 4). Patients born in Oceania and North America were prescribed injectable drugs for pain relief in end-of-life care significantly more often than others. Patients born in Nordic countries were prescribed anxiolytic drugs less often. They were also prescribed anticholinergic drugs to a lesser extent, similar to those from Slavic and Eastern European countries.

Systematic assessment for the presence of pain by Numerical Rating Scale (NRS), Visual Analogue Scale (VAS), or other validated instrument) was performed more often in patients of Slavic and Eastern European origin and less often for patients born in Nordic countries. Moreover, systematic assessment for other symptoms than pain (by NRS, VAS, or other validated instrument) was performed significantly more often in foreign-born persons from South and Central America. Regarding assessment of oral health was done in lesser degree in patients born in Nordic and Slavic and Eastern European countries (Table 5).

Use of palliative consultation services in end-of-life care

The differences in the use of palliative consultation services in the last week of life are shown in Table 6. Consultation with a spiritual counselor took place significantly less often in Swedish-born patients compared with foreign-born groups, except a higher consultation degree than patients born in the Nordic countries. On the other hand, there was a higher degree of consultations with palliative care teams for Swedish-born patients than patients born in Africa and Asia.

Table 2. Areas of country of birth

Areas of country of birth[a]	*n*	%
Sweden	72.012	88.4
Middle East	646	0.8
Western Europe	1.473	1.8
Nordic	4.379	5.4
Africa	207	0.2
Slavic and Eastern Europe	2.061	2.5
South and Central America	183	0.2
Asia	259	0.3
Oceania and North America	187	0.2
Invalid	11	0.1
Total	**81.418**	

[a] Areas of country of birth, see Supplementary Appendix 1 for the complete list of countries included in the study.

Table 3. Description of data about quality indicators during the last week of life divided into Swedish-born and foreign-born patients

	Swedish-born		Foreign-born	
	72.012		9.396	
Category	*n*	%	*n*	%
Prescribed rescue medication				
Pain	67.227	*94.1*	8.763	*94.0*
Rattle	59.675	*84.2*	7.748	*83.9*
Nausea	65.049	*91.3*	8.473	*91.1*
Anxiety	65.733	*92.2*	8.525	*91.7*
Symptom assessment				
Pain	33.045	*49.8*	4.529	*52.1*
Symptom other than pain	19.140	*30.1*	2.657	*31.8*
Oral health	47.002	*72.7*	6.212	*73.1*
Consultations				
Pain unit	548	*0.8*	82	*0.9*
Palliative care specialists	5.639	*7.8*	709	*7.5*
Spiritual counselor	437	*0.6*	111	*1.2*
Medical decision is documented	48.616	*67.5*	6.363	*67.7*
End-of-life communication				
Patient	38.197	*53.1*	5.303	*56.4*
Do not know	6.841	*9.5*	795	*8.5*
Family	54.812	*76.1*	7.369	*78.4*
Do not know	5.045	*7.0*	592	*6.3*
Preferred place of death known	30.122	*41.8*	4.038	*42.9*
Do not know	24.466	*34.0*	3.085	*32.8*
Bereavement follow-up was offered				
Yes	47.344	*65.7*	6.315	*65.2*
No	10.498	*14.6*	1.349	*14.3*
Do not know	13.203	*18.3*	1.545	*16.4*
Anyone present at time of death				
None	11.541	*16.0*	1.509	*16.9*
Relatives	26.031	*36.1*	3.663	*39.0*
Relatives and health care staff	13.243	*18.3*	13.243	*18.3*
Health care staff	19.884	*27.6*	2.334	*24.8*
Do not know	1.313	*1.8*	176	*1.9*

End-of life communication, medical decision-making, bereavement support, presence at time of death, and knowledge of patients' preferred place of death

Dialogue and end-of life discussions with the family were more often held by relatives of patients born in the Middle East. No difference was found relating to dialogue and end-of life discussions with the patients as well as the presence of a medical decision about end-of-life care in patients' records (Table 7).

The quality indicator, presence of someone at time of death, is presented in two different panels (Table 8). The first panel shows dying in the presence of someone (either family member/health care staff or both), and the second panel shows dying in the presence of a family member (family and family member and health care staff). The likelihood of dying in the presence of family members was more frequently occurring in care of patients born in the Middle East and less often for patients born in Nordic and Slavic and Eastern European countries. Dying in the presence of someone was more likely for patients born in Middle east and less often for patients born in nordic countries. Relatives of patients born in Nordic countries were offered bereavement support in a lesser degree.

Discussion

The main result of this study was that there are no general patterns in differences in the quality of end-of-life care between Swedish-born and foreign-born patients. However, there were several significant differences in various quality indicators but not in a specific direction. Sometimes, quality indicators were an advantage for Swedish-born patients but just as often, they were favorable for foreign-born patients as well.

The results showed that foreign-born patients were less likely to be cared for in specialized palliative care units than Swedish-born patients. These results are in agreement with other studies that compare the utilization of specialized palliative care services between immigrants and native-born persons (Koffman et al., 2014; Henke et al., 2017) or between different ethnic groups (Cohen, 2008; Coupland et al., 2011). Access to specialized palliative care is often taken as a proxy for the quality of end-of-life care (Coupland et al., 2011). These assumptions are supported by the results from the Swedish Registry of Palliative Care (2018), which showed that specialized palliative care units do better in all, but one (pressure ulcers) quality indicator. The result also showed a little over representation of cancer diagnosis in foreign-born patients. Register studies from the SRPC have shown that patients with cancer receive better quality of end-of-life care in several end-of-life care areas when compared with patients dying with dementia (Martinsson et al., 2017), respiratory disease

Table 4. End-of-life prescriptions of injectable drugs for symptom relief

Areas of country of birth	Analgesic			Antiemetic			Anxiolytic			Anticholinergic		
	OR	(CI)	*p*	OR	(CI)	*p*	OR	(CI)	*p*	OR	(CI)	*p*
Sweden (ref)												
Middle East	0.88	0.63–1.24	NS	1.09	0.82–1.47	NS	0.90	0.67–1.22	NS	1.07	0.83–1.36	NS
Western Europe	0.97	0.77–1.22	NS	0.99	0.82–1.2	NS	0.96	0.78–1.17	NS	0.93	0.8–1.01	NS
Nordic	0.90	0.79–1.02	NS	0.96	0.86–1.08	NS	0.85	0.76–0.95	<0.01	0.89	0.82–0.97	<0.01
Africa	1.1	0.55–2.17	NS	0.96	0.59–1.6	NS	0.79	0.47–1.34	NS	0.88	0.58–1.36	NS
Slavic and Eastern Europe	0.94	077–1.14	NS	0.89	0.76–1.04	NS	0.86	0.73–1.01	NS	0.85	0.74–0.96	<0.01
South and Central America	0.66	0.35–1.13	NS	0.97	0.55–1.7	NS	0.62	0.37–1.05	NS	0.73	0.47–1.12	NS
Asia	0.91	0.51–1.63	NS	0.91	0.58–1.40	NS	1.11	0.64–1.90	NS	1.0	0.67–1.5	NS
Oceania and North America	3.4	1.09–10.8	<0.05	1.62	0.82–3.19	NS	1.44	0.73–2.84	NS	0.94	0.61–1.44	NS

Expressed in odds ratio with 95% CIs. Presentation of model 4.
Odds ratio adjusted for age, gender, diagnosis, and the type of the end-of-life care unit.

Table 5. Systematic assessment of symptoms

Areas of country of birth	Pain assessed[a]			Other symptoms[a]			Status of mouth		
	OR	(CI)	*p*	OR	(CI)	*p*	OR	(CI)	*p*
Sweden (ref)									
Middle East	0.97	0.81–1.16	NS	1.02	0.85–1.22	NS	0.96	0.79–1.17	NS
Western Europe	1.10	0.98–1.24	NS	1.09	0.97–1.2	NS	1.06	0.93–1.2	NS
Nordic	0.93	0.87–0.99	<0.05	0.98	0.91–1.05	NS	0.92	0.85–0.99	<0.05
Africa	0.75	0.55–1.02	NS	0.67	0.63–1.2	NS	0.83	0.59–1.17	NS
Slavic and Eastern Europe	1.10	1.0–1.22	<0.05	0.99	0.89–1.1	NS	0.90	0.80–0.99	<0.05
South and Central America	1.13	0.82–1.57	NS	1.40	1.01–1.92	<0.05	1.13	0.76–1.66	NS
Asia	0.96	0.73–1.28	NS	0.91	0.68–1.21	NS	0.90	0.66–1.22	NS
Oceania and North America	0.92	0.67–1.26	NS	0.87	0.62–1.22	NS	0.85	0.61–1.19	NS

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Odds ratio adjusted for age, gender, diagnosis, and the type of the end-of-life care unit.
[a]Assessed systematic by validated instruments.

(Ahmadi et al., 2015, 2016), and heart disease (Brännström et al., 2011). However, the statistics, in the present study, are adjusted for the type of end-of-life care unit and diagnosis.

The most unexpected result was that Nordic-born patients scored lower on almost all quality indicators compared with Swedish-born patients, despite them coming from countries with a low cultural distance [dissimilarities in language, social structure (e.g., family), religion, standard of living, and cultural values (Triandis, 2000)]. There might be great linguistic differences, especially between Finish and Swedish people. Finnish-born migrants dominated in the Nordic group ($n = 2{,}941/4{,}379$, 67%), as in the Swedish migrant population (Statistics Sweden, 2019). Finns immigrated to Sweden during the 1970s as labor migrants and most were Finnish-speaking. Previous longitudinal epidemiologic studies (Albin et al., 2005, 2006) have shown higher mortality and morbidity in foreign-born compared with Swedish-born persons, particularly among migrants from Finland. A larger number of deaths in the ICD code group "Symptoms, signs and ill-defined conditions" could especially be explained by language problems, but they might also be related to cultural factors affecting communication. Thus, migrants might express health, illness, and pain differently from native Swedes. However, there is no clear explanation for these differences, which is why further studies are needed.

The difference in offering consultations with spiritual counselor, being of a lesser extent for Swedish-born persons, is striking and may be due to the fact that Swedes are the most secularized people in the world (World Values Survey, 2014). Another explanation could be found in the study by Strang et al. (2001), which shows that many nurses in their study thought that Swedish patients, compared with foreign-born patients, did not have specific spiritual needs. However, it was a very low proportion in all

Table 6. Use of palliative consultation services in end-of-life care

	Palliative care team			Pain specialist			Spiritual counselor		
Areas of country of birth	OR	(CI)	*p*	OR	(CI)	*p*	OR	(CI)	*p*
Sweden (ref)									
Middle East	0.77	0.58–1.05	NS	0.89	0.45–1.76	NS	3.67	2.26–5.97	<0.001
Western Europe	0.97	0.79–1.99	NS	0.83	0.45–1.6	NS	2.50	1.64–3.82	<0.001
Nordic	0.97	0.86–1.1	NS	1.14	0.81–1.6	NS	0.52	0.30–0.88	<0.05
Africa	0.39	0.22–0.70	<0.001	0.52	0.16–1.68	NS	2.12	0.80–5.96	NS
Slavic and Eastern Europe	0.90	0.75–1.07	NS	0.87	0.54–1.4	NS	2.14	1.47–3.11	<0.001
South and Central America	1.11	0.65–1.89	NS	0.56	0.08–4.05	NS	4.70	2.07–10.71	<0.001
Asia	0.60	0.37–0.96	<0.05	0.74	0.27–2.09	NS	6.16	3.45–11.0	<0.001
Oceania and North America	0.66	0.34–1.27	NS	0.78	0.11–5.66	NS	2.62	0.83–8.25	NS

Expressed in odds ratio with 95% CIs. Presentation of model 4.
Odds ratio adjusted for age, gender, diagnosis, and the type of the end-of-life care unit.

Table 7. End-of life communication and the medical decision to focus on end-of-life care are documented in patient record

	EOL communication			EOL communication			Medical decision-making		
	Patient			Family					
Areas of country of birth	OR	(CI)	*p*	OR	(CI)	*p*	OR	(CI)	*p*
Sweden (ref)									
Middle East	1.06	0.84–1.33	NS	1.37	1.07–1.93	<0.05	1.22	0.91–1.63	NS
Western Europe	1.09	0.95–1.26	NS	1.22	0.98–1.36	NS	0.98	0.81–1.19	NS
Nordic	0.98	0.91–1.06	NS	0.95	0.87–1.04	NS	0.97	0.87–1.08	NS
Africa	1.02	0.67–1.54	NS	1.83	0.98–3.41	NS	1.15	0.67–1.97	NS
Slavic and Eastern Europe	0.96	0.85–1.08	NS	1.12	0.97–1.28	NS	0.94	0.8–1.1	NS
South and Central America	1.14	0.74–1.75	NS	1.35	0.79–2.29	NS	0.98	0.57–1.69	NS
Asia	0.99	0.68–1.46	NS	1.46	0.89–2.39	NS	1.32	0.79–2.19	NS
Oceania and North America	0.91	0.63–1.3	NS	1.42	0.88–2.28	NS	1.1	0.59–1.68	NS

Expressed in odds ratio with 95% CIs. Presentation of model 4.
Odds ratio adjusted for age, gender, diagnosis and the type of the end-of-life care unit.

groups. The lower frequency of involvement by palliative care teams in caring especially for African and Asian born patients is hard to explain, These results indicate that foreign-born patients are disadvantaged, in terms of having poorer access to palliative care expertise. Immigrant patients might be less familiar with palliative care and lack of knowledge about the healthcare system in the new country might be obstacles in requesting and placing a demand on specialized care. Another explanation might be that many migrants with severe conditions and in palliative stage are cared for in their homes with the help of their relatives, as demonstrated in previous studies of Turkish and Moroccan immigrants (de Graaff et al., 2010, 2012).

End-of-life communication with patients and/or relatives, when informing about imminent death and making advance care planning for the remaining time in life, is considered as a cornerstone in palliative care. Moreover, the National Board of Health and Welfare (Socialstyrelsen. Nationella riktlinjer-utvärdering, 2016) in Sweden has listed end-of-life communication as one of six quality indicators of palliative care. We found no significant difference in end-of-life communication with the patients, and the only significant difference was that the families of patients born in Middle East, were more likely to have had an end-of-life communication. Their family members were in a higher degree present at time of death. Family involvement in end-of-life care might be seen as a shared responsibility in the society and a duty in many foreign cultures (de Graaff et al., 2010, 2012; Hiruy and Mwari, 2014; Javdan and Cassileth, 2016).

The presence of someone at the time of death, that is, the patient does not die alone has a high value in all cultures. In Sweden, it is not unusual that if the patient does nothas any relative that could be present, a total stranger (extra staff) could be called in to sit by the deathbed. A recent study from Sweden (Strang et al., 2020) about COVID-19 deaths, with data from the SRPC, has an extensive discussion about this topic as many patients are dying due to COVID-19 or died alone due to restrictions on visits.

Table 8. The patients' preferred place of death is known, someone present at time of death and bereavement support

Areas of country of birth	Preferred place of death			Present at time of death[a]			Present at time of death[b]			Bereavement support		
	OR	(CI)	*p*	OR	(CI)	*p*	OR	(CI)	*p*	OR	(CI)	*p*
Sweden (ref)												
Middle East	0.76	0.58–0.99	<0.05	1.67	1.28–2.19	<0.001	2.01	1.53–2.64	<0.001	0.97	0.74–1.27	NS
Western Europe	0.88	0.75–1.02	NS	1.04	1.0–1.2	NS	1.05	0.9–1.22	NS	0.98	0.82–1.16	NS
Nordic	0.92	0.84–1.01	NS	0.86	0.8–0.94	<0.001	0.84	0.77–0.92	<0.001	0.88	0.8–0.96	<0.01
Africa	0.89	0.57–1.39	NS	1.48	0.92–2.36	NS	1.59	0.98–2.55	NS	0.95	0.56–1.62	NS
Slavic and Eastern Europe	1.03	0.89–1.19	NS	0.89	0.79–1.0	NS	0.84	0.74–0.96	<0.01	0.93	0.81–1.07	NS
South and Central America	0.86	0.54–1.36	NS	1.37	0.86–2.18	NS	1.6	1.0–2.57	NS	1.47	0.84–2.6	NS
Asia	0.68	0.46–1.02	NS	1.31	0.87–1.95	NS	1.45	0.96–2.19	NS	1.04	0.66–1.63	NS
Oceania and North America	0.84	0.55–1.22	NS	1.13	0.74–1.73	NS	1.06	0.68–1.66	NS	0.97	0.61–1.54	NS

Expressed in odds ratio with 95% CIs. Presentation of model 4.
Odds ratio adjusted for age, gender, diagnosis, and the type of the end-of-life care unit.
[a] Either family member/health care staff or both.
[b] Only relatives or relatives and health care staff.

Strengths and limitations

The main strength of this study is that the SRPC is a national register that covers a majority of deaths from all parts of Sweden and care facilities and registers several indicators for the quality of end-of-life care. Further, SRPC became a quality register in 2006 and has since been continuously evaluated, revised, and validated (Martinsson et al., 2011; Lundström et al., 2012); also, it has a coverage of approximately 60% of all deaths in Sweden. Another strength is the Swedish personal identification number, which allows for registers to be coordinated. In this study, the SRPC and the Swedish Cause of Death Register make it possible to identify country of birth.

The limitation of the present study is that all data were, retrospectively, reported by staff and based on documentation in the medical record; no patient-reported data were present. Furthermore, it was challenging to know how to group countries together, especially countries from the former Eastern Bloc of Europe; perhaps, the grouping could have been done differently. However, what was finally chosen was based on the fact that most of the deceased persons in the present study were old and had migrated to Sweden during a long and turbulent time when countries and borders in Europe underwent several changes.

Conclusion

Foreign-born patients were less likely to be cared for in specialized palliative care units than Swedish-born patients, despite a higher proportion of those with cancer diagnosis. However, no general patterns were found indicating that foreign-born patients were disadvantaged using the quality indicators measured in the present study. Perhaps, this is an indication that palliative care in Sweden is individualized; nonetheless, the quality of end-of-life care would be higher if dying patients, regardless of country of birth, have better access to specialized palliative care.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1478951521000110.

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