Factors influencing place of death and disenrollment among patients receiving specialist palliative care

Marco Di Nitto[1], Marco Artico[2], Michela Piredda[3], Maddalena De Maria[1], Caterina Magnani[4], Anna Marchetti[3], Chiara Mastroianni[5], Roberto Latina[6], Maria Grazia De Marinis[3], Daniela D'Angelo[7]

[1]Department of biomedicine and prevention, University of Rome "Tor Vergata", Rome, Italy; [2]Department of Palliative Care and Pain Therapy Unit, Azienda ULSS n.4 Veneto Orientale, San Donà di Piave, Italy; [3]Research Unit Nursing Science, Campus Bio-Medico di Roma University, Rome, Italy; [4]Local health unit Roma 1, Rome, Italy; [5]Fondazione Campus Bio-Medico, Rome, Italy; [6]Deptment of Health Promotion Sciences, Maternal & Infant Care, Internal Medicine & Excellence Specialists University of Palermo, Palermo, Italy; [7]National Institute of Health, Rome, Italy.

Abstract. *Background and aim of the work:* Place of death and disenrollment from specialized palliative care services (SPCSs) are two aspects that determine service utilization. These aspects should be determined by patient needs and preferences, but they are often associated to patient sociodemographic or contextual characteristics. The aim of this study was to describe which factors are associated with utilizing SPCSs in terms of place of death and disenrollment. *Methods*: Retrospective cohort study. Patients (>18 years) who died or were disenrolled during SPCSs utilization. Two hierarchical regression models were performed, and variables were categorized in predisposing, enabling, and need factors according to the Andersen behavioral model of health services use. *Results:* We included 35,869 patients (52,5% male, mean age 74,6 ± 12,3 SD), where 17,225 patients died in hospice and 16,953 at home, while 1,691 patients were disenrolled. Dying at home was associated with older age, oncological diagnosis, painful symptoms and longer survival time. Instead, service disenrollment was associated with less education, longer wait time and longer length of stay. *Conclusions:* SPCS utilization was not influenced only by patient need, but also by other factors, such as social and contextual factors. These factors need to be considered by health care providers and efforts are needed for 1) identifying barriers and implementing effective interventions to support patients and caregivers in their preferred place of care and death and 2) for avoiding SPCS disenrollment with an increased probability of aggressive treatments and worse quality of life for *patients.* (www.actabiomedica.it)

Key words: Andersen's behavioural model of health services use, place of death, patient discharge, palliative care, facilities and services utilization, logistic models, retrospective studies.

Introduction

Palliative care is provided at different levels, from basic management of symptoms and communication skills regarding end of life, to specialised palliative care services (SPCSs), which provide consultation and home and residential palliative care (1). As this field is constantly evolving, new challenges are emerging, leading researchers and clinicians to think about solutions that ensure continuous care for all patients with palliative care needs.

Continuous specialised palliative care activities are provided in the community and residential settings to ensure that patients' complex needs are met for as long as possible, ideally until death (2,3). Currently, among the most concerning aspects of palliative care utilization are place of death (4,5) and service disenrollment (6).

Place of death is often considered as an outcome of SPCSs, and home death is viewed optimal in terms of quality of life, symptom control and cost-savings (4). Indeed, terminally ill patients, and their caregivers in most cases, prefer death to occur at home (7-9). Although the patient's clinical characteristics and preferences should determine the place of death (10), several studies found that other factors, such as older age (11-13), a proper home arrangement (14), living in rural areas (15,16) and high income (16) play an important role in determining where people will die (8).

Disenrollment from SPCS prior to patient death may be undertaken either by the SPCS team (e.g. the patient no longer meets the eligibility criteria) or the patient themselves (i.e. the patient seeks life-prolonging therapies), and it has been associated with hospitalisation (mainly in emergency departments and intensive care units), determining hospital death (17,18) and worse patient outcome (6). Moreover, disenrollment may be an indicator of poor quality of care perceived by patient/caregivers and can determine discontinuity of care during disease progression. Disenrollment may also generate patient and family burden and an increase in cost. Previous studies have outlined how palliative care service disenrollment varied by age, race, gender and diagnosis (19,20), and that hospice-level characteristics play important roles (21,22).

Place of death and disenrollment from SPCSs are influenced by multiple factors whose understanding is important when ensuring that service utilization is primarily driven by patient and caregiver needs (23). However, few studies have systematically investigated the association of these factors after referral to an SPCS using a conceptual framework. Therefore, we sought to describe which individual and contextual factors were associated with SPCS utilization in terms of place of death and patient disenrollment using the Andersen behavioural model of health services.

Methods

Study design

This study was a retrospective cohort study, which followed the Strengthening the Reporting of Obser-

vational Studies in Epidemiology (STROBE) recommendations (24).

Data source and setting

Retrospective data were collected between 2012 and 2016 in 19 SPCSs within the Lazio region, Italy. It is possible to find more information on how data of the enrolled SPCSs were retrieved and collected in our previous work (25). In Italy, palliative care is universally provided free of charge, as it is considered an essential level of care (LEA) by the National Healthcare System, and every SPCS includes integrated services, such as consulting (i.e. palliative care team consultation within health services) and home and residential care (hospice). Therefore, each SPCS guarantees palliative care 24 hours per day, seven days per week in a hospice, and access to at least one healthcare provider per day at home with the option to contact the service at any time (availability 24 hours per day).

Conceptual framework

To analyse the SPCS utilization and its factors, the Andersen behavioural model of health services was used (26). This model has been widely used to identify factors of health services use in various settings, including dentistry (27-29), mental health (30-32) and cancer screening (33-35). Moreover, it has been successfully utilised in palliative care (12,36-38).

Study sample

Inclusion criteria included patients: (1) >18 years old; (2) residing in the Lazio region; and (3) who died within or disenrolled from SPCSs.

Data from 36,457 patients were collected. Among these, 588 patients were excluded because they did not meet the inclusion criteria. The final sample consisted of 35,869 individuals. Data regarding disenrollment came only from 10 (52%) out of the 19 SPCSs included due to missing information. To minimise selection bias, all patients who died within or disenrolled from SPCSs were analysed.

Independent variables

Data concerning gender, age, education, diagnosis, source of referral, survival time (days), length of stay (days), wait time (days), symptoms/signs and place of death and/or disenrollment were collected. These variables were chosen for two main reasons: (1) they were among those that the Italian Ministry of Health strongly recommends being collected from each SPCS (2) their theoretical association with place of death and disenrollment.

According to Andersen's model, the factors were classified as: (1) predisposing, (2) enabling or (3) needs.

(1) Predisposing factors included sociodemographic variables, such as age, gender and level of education. Patients' age was grouped into four main groups: < 67, 67–76, 77–83 and > 83 years. Gender was dichotomised as female versus male, while education was dichotomised as ≤ 8 years (i.e. lower education) versus > 9 years (i.e. higher education).

(2) Enabling factors referred to all variables (i.e. systemic or structural) required to utilise the healthcare system. In this study, we considered the enabling factors as the wait time for SPSC admission and the source of referral. When we refer to wait time for SPCS admission, we mean the time (in days) elapsed from the request to take charge of the patients up to their effective enrolment in SPCS. Following the Italian national indicators of palliative care (39), this variable was dichotomised as individuals with a wait time < 3 days versus individuals with a wait time ≥ 3 days. The source of referral was also dichotomised as individuals coming from home versus individuals coming from acute or long-term care facilities.

(3) Needs factors referred to all variables that could result in a need to access to health services (i.e. type and severity of illness). For the purposes of this study, we included in this category, symptoms, survival time/length of stay in the SPCS and diagnosis. Symptoms, conventionally classified by the Italian Ministry of Health (40) and mandatorily collected by all palliative care centres, were aggregated into five groups: pain, dyspnoea, consciousness disorders, bowel/bladder dysfunction and others. We defined survival time as the period (in days) that individuals spent in the SPCS from enrolment until death, intending this variable as proxy of disease severity. In case individuals disenrolled, we considered the same variable as 'length of stay', as these individuals did not die in the SPCS. Following previous literature (41), this variable was dichotomised as individuals with survival time/length of stay in the SPCSs < 15 days versus individuals with survival time/length of stay ≥ 15 days. Lastly, diagnosis was dichotomised as oncological versus non-oncological.

Dependent variables

To analyse the SPCS utilization, place of death and disenrollment from SPCS were used as dependent variables. Place of death was dichotomised as hospice versus home, while disenrollment was dichotomised as individuals who died in the service versus individuals disenrolled from SPCS before their death.

Statistical analysis

Descriptive statistics (i.e. means, standard deviations, frequency and percentages) were used to describe the patients' sociodemographic and clinical characteristics.

A set of preliminary analyses preceded the hierarchical regression models. In particular, the presence of missing data was evaluated to minimise information bias. To verify the possibility that data were missing completely at random (MCAR), Little's test (42) was used. Thus, we calculated the percentage of missing values on the different variables and tested the plausibility of missingness at random (MAR) by examining the patterns of missingness and the possible predictability of missing data in each variable by all the variables in the model. Consistent with recent developments (43), the Bayesian estimation method was used for the multiple imputations.

Place of death (hospice = 0, home = 1) and disenrollment from the SPCS (died within the SPCS = 0, disenrolled = 1) were used as dependent variables for the first and the second hierarchical regression, respectively. For this reason, we employed logistic regression. Each regression included all the independent variables above described organized in the three factors (predisposing, enabling and needs) according to the Andersen model.

The results of logistic regression were represented as the odds ratios (ORs) with 95% confidence intervals (95% CIs) and p-values. The software SPSS version 26.0 (IBM® SPSS® Statistics, USA) was used for analyses.

Ethical approval

The study was approved by the Ethics Committee of Campus Bio-Medico University of Rome (Protocol 7/17 OSS ComEt CBM).

Results

Preliminary analysis

Little's test was significant ($\chi^2(9) = 50.468$; $p < 0.001$), suggesting evidence of systematic missingness. Thus, under the missingness at random (MAR) assumption, we imputed the missing data of the response variable using chained equations with 100 imputed datasets. All results were aggregated according to Rubin's rule. The complete case analyses

Table S1. Complete case analysis of factors related to patients' death in hospice versus home according to Andersen's Model (n=3097).

	Block 1 PREDISPOSING			Block 2 ENABLING			Block 3 NEED		
	OR	p	CI 95%	OR	p	CI 95%	OR	p	CI 95%
Gender									
F	0.92	0.234	0.79-1.06	0.89	0.134	0.77-1.03	0.88	0.087	0.76-1.02
M	Ref			Ref			Ref		
Age (completed years)									
<67	Ref			Ref			Ref		
67-76	1.09	0.394	0.89-1.35	0.99	0.894	0.79-1.22	0.96	0.736	0.77-1.20
77-83	1.53	<0.001	1.23-1.89	1.27	0.032	1.02-1.59	1.22	0.088	0.97-1.52
>83	2.08	<0.001	1.68-2.58	1.65	<0.001	1.32-2.06	1.61	<0.001	1.28-2.02
Education (years)									
≤8	0.90	0.260	0.76-1.08	1.26	0.019	1.04-1.52	1.23	0.035	1.01-1.49
>9	Ref			Ref			Ref		
Wait time (days)									
< 3				Ref			Ref		
≥ 3				0.83	0.023	0.71-0.97	0.83	0.027	0.71-0.98
Source of referral									
Home				Ref			Ref		
Acute/long-term care				0.32	<0.001	0.27-0.39	0.35	<0.001	0.29-0.42
Symptoms									
Pain							Ref		
Dyspnea							0.80	0.116	0.61-1.06
Consciousness disorders							0.91	0.434	0.71-1.16
Bowel/bladder dysfunction							0.84	0.360	0.58-1.22
Other symptoms							0.70	<0.001	0.59-0.84
Survival time (days)									
<15							Ref		
≥ 15							1.65	<0.001	1.42-1.92
Diagnosis									
Non-oncological							Ref		
Oncological							0.94	0.573	0.77-1.15

Legend: OR: Odd Ratio; CI: Confidence Interval.

Table S2: Complete case analysis of factors related to patients not disenrolled versus disenrolled from SPCS according to Andersen's Model (n=2261).

	Block 1 PREDISPOSING			Block 2 ENABLING			Block 3 NEED		
	OR	p	CI 95%	OR	P	CI 95%	OR	P	CI 95%
Gender									
F	1.39	0.088	0.95-2.03	1.39	0.094	0.95-2.03	1.33	0.143	0.91-1.96
M	Ref			Ref			Ref		
Age (completed years)									
<67	Ref			Ref			Ref		
67-76	1.09	0.790	0.58-2.02	1.02	0.952	0.55-1.89	0.98	0.958	0.53-1.83
77-83	1.07	0.845	0.56-2.02	0.91	0.765	0.48-1.72	0.85	0.621	0.45-1.62
>83	2.45	0.002	1.40-4.30	2.18	0.007	1.24-3.82	2.07	0.013	1.17-3.67
Education (years)									
Lower education	0.77	0.384	0.43-1.38	0.96	0.901	0.54-1.73	0.92	0.768	0.51-1.65
Higher education	Ref			Ref			Ref		
Wait time (days)									
< 3 days				Ref			Ref		
≥ 3 days				1.00	0.986	0.68-1.47	0.95	0.794	0.65-1.40
Source of referral									
Home				Ref			Ref		
Acute/long-term care				0.32	<0.001	0.21-0.48	0.34	<0.001	0.22-0.50
Survival time (days)									
<15							Ref		
≥ 15 days							1.79	0.005	1.19-2.69
Diagnosis									
Non-oncological							Ref		
oncological							0.88	0.684	0.47-1.64

Legend: OR: Odd Ratio; CI: Confidence Interval.

are reported in the supplementary material (Table S1 and S2).

Sample

Our sample included 35,869 patients. More than half were male (52.5%) and older than 67 years (77.1%) with mostly (80.2%) ≤ 8 years of education (i.e. primary- or lower-secondary-school level). Regarding clinical characteristics, 86.7% of the patients had an oncological diagnosis. The most frequent symptoms were pain (33%) and consciousness disorders (13%). Most patients (67.9%) moved from acute or long-term care, with a wait time for SPCS admission of longer than 3 days (61.6%).

Considering the subgroup of patients who died in SPCS (n = 34,178), more than half (56.0%) had a survival time ≥ 15 days, with a nearly equal distribution of death occurring at home (50.4%) or in hospice (49.6%).

Most patients disenrolled from the SPCSs (*n* = 1,691) were discharged to be enrolled in either a hospital (20.9%) or long-term care facility (12.2%); some patients revoked their care (20.3%). The total rate of disenrollment from the SPCSs was 7.53% (referring to 10/19 SPCSs analysed) (Table 1).

Factors related to place of death

Table 2 shows the results of the three-stage hierarchical logistic-regression model regarding place of death.

Table 1. Participant characteristics (n = 35869)

	n	%
Gender		
F	14696	47.5%
M	16235	52.5%
Age (completed years)		
<67	6763	22.9%
67-76	7753	26.3%
77-83	7478	25.4%
>83	7497	25.4%
Education (years)		
≤8	8956	80.2%
>9	2209	19.8%
Diagnosis		
Non-oncological	4105	13.3%
oncological	26652	86.7%
Symptoms		
Pain	2991	33.0%
Dyspnea	831	9.2%
Agitation/drowsiness	1218	13.4%
Bowel/bladder dysfunction	391	4.3%
Other symptoms	3644	40.2%
Source of referral		
Home	8514	32.1%
Acute/long-term care	17976	67.9%
Wait time (days)		
<3	6747	38.4%
≥3	10801	61.6%
Survival time/length of stay (days)		
<15	15268	44.0%
≥15	19405	56.0%
Place of death (n=34178)		
Home	17225	50.4%
Hospice	16953	49.6%
Disenrollment (n=22466)+		
Yes	1691	7.53%
No	20775	92.47%
Cause of disenrollment		
Revoked care	343	20.3%
Acute care	354	20.9%
Long term care	207	12.2%
Not specified	787	46.5%
+ These results are referred to 10 out of 19 SPCS analyzed.		

Block 1 demonstrated that one predisposing factor was significantly associated with place of death. Specifically, people aged ≥ 67 years were more likely to die at home than people aged < 67 years. The statistical significance remained almost unchanged across each of the age groups analysed (67–76, 77–83 and > 83).

Block 2 showed that three enabling factors were significantly related to place of death: age, wait time and source of referral. Patients aged between 67 and 76 and those over 83 were more likely to die at home than those under 67 (OR: 1.15; 95% CI: 1.07–1.23 and OR: 1.11; 95% CI: 1.03–1.19, respectively). Individuals with a wait time ≥ 3 days were more likely to die at home than people with a shorter wait time (OR: 1.41; 95% CI: 1.30–1.53). The source of referral showed that individuals who were referred to an SPCS by a hospital or a long-term care facility were less likely (56%) to die at home (OR: 0.44; 95% CI: 0.41–0.46) compared to those referred from home.

Block 3 showed that all needs factors (symptoms, survival time, diagnosis) were associated with place of death. Specifically, people suffering from dyspnoea (OR: 0.74; 95% CI: 0.63–0.86), consciousness disorders (OR: 0.70; 95% CI: 0.56–0.87), and bowel/bladder dysfunction (OR: 0.72; 95% CI: 0.56–0.92) were less likely (26%, 30% and 28%, respectively) to die at home than those suffering from pain. Individuals with a survival time ≥ 15 days were more likely to die at home (OR: 1.92; 95% CI: 1.83–2.01) compared to those with a survival time < 15 days; oncological patients were more likely to die at home than individuals with non-oncological diseases (OR: 1.51; 95% CI: 1.41–1.63).

Factors related to disenrollment from SPCS

Table 3 shows the results of the three-stage hierarchical logistic-regression model regarding the disenrollment from SPCSs.

In Block 1, age and education level showed a significant association. Specifically, patients aged between 77 and 83 years were less likely (38%) to be disenrolled from the SPCSs (OR: 0.62; 95% CI:0.50–0.77) compared to those aged < 67 years; in addition, individuals with ≤ 8 years of education were more likely to be

Table 2. Factors related to patients' death in hospice versus home according to Andersen's Model (n=34178).

	Block 1 PREDISPOSING			Block 2 ENABLING			Block 3 NEED		
	OR	p	CI 95%	OR	p	CI 95%	OR	p	CI 95%
Gender									
F	1.01	0.550	0.97-1.06	1.01	0.742	0.96-1.06	0.99	0.684	0.94-1.04
M	Ref			Ref			Ref		
Age (completed years)									
<67	Ref			Ref			Ref		
67-76	1.20	<0.001	1.12-1.28	1.15	<0.001	1.07-1.23	1.13	0.001	1.05-1.21
77-83	1.20	<0.001	1.12-1.28	1.07	0.060	1.00-1.15	1.07	0.088	0.99-1.15
>83	1.27	<0.001	1.19-1.36	1.11	0.005	1.03-1.19	1.14	<0.001	1.06-1.23
Education (years)									
≤8	0.95	0.182	0.89-1.02	1.02	0.622	0.95-1.10	0.99	0.767	0.91-1.07
>9	Ref			Ref			Ref		
Wait time (days)									
< 3				Ref			Ref		
≥ 3				1.41	<0.001	1.30-1.53	1.38	<0.001	1.27-1.49
Source of referral									
Home				Ref			Ref		
Acute/long-term care				0.44	<0.001	0.41-0.46	0.44	<0.001	0.42-0.47
Symptoms									
Pain							Ref		
Dyspnea							0.74	<0.001	0.63-0.86
Consciousness disorders							0.70	0.002	0.56-0.87
Bowel/bladder dysfunction							0.72	0.008	0.56-0.92
Other symptoms							0.96	0.364	0.87-1.05
Survival time (days)									
<15							Ref		
≥ 15							1.92	<0.001	1.83-2.01
Diagnosis									
Non-oncological							Ref		
Oncological							1.51	<0.001	1.41-1.63

Legend: OR: Odd Ratio; CI: Confidence Interval.

disenrolled from the SPCSs (OR: 1.42; 95% CI: 1.07–1.88) than individuals with > 9 years of education.

In block 2, age, education and a longer wait time were significantly associated with disenrollment from SPCSs. Indeed, patients with a wait time ≥ 3 days were more likely to be disenrolled from the SPCSs (OR: 1.85; 95% CI: 1.58–2.17) than those with a wait time < 3 days; individuals referred by the hospital or long-term facilities were less likely (34%) to be disenrolled

from SPCSs (OR: 0.66; 95% CI: 0.58–0.75) compared to those referred from home.

In Block 3, age, education, wait time until SPCS admission, sources of referral and 'length of stay' were significantly associated with disenrollment from SPCSs. Specifically, patients who spent more than 15 days in SPCSs had a higher likelihood to be disenrolled (OR: 1.35; 95% CI: 1.21–1.50) than patients who spent less than 15 days.

Table 3. Factors related to patients not disenrolled versus disenrolled from SPCS according to Andersen's Model (n=22466).

	Block 1 PREDISPOSING			Block 2 ENABLING			Block 3 NEED		
	OR	p	CI 95%	OR	P	CI 95%	OR	P	CI 95%
Gender									
F	1.10	0.083	0.99-1.23	1.09	0.108	0.98-1.22	1.08	0.171	0.97-1.21
M	Ref			Ref			Ref		
Age (completed years)									
<67	Ref			Ref			Ref		
67-76	0.84	0.055	0.70-1.00	0.80	0.017	0.67-0.96	0.79	0.014	0.66-0.95
77-83	0.62	<0.001	0.50-0.77	0.57	<0.001	0.46-0.71	0.56	<0.001	0.45-0.70
>83	0.99	0.902	0.83-1.18	0.90	0.245	0.75-1.08	0.87	0.134	0.72-1.04
Education (years)									
≤8	1.42	0.016	1.07-1.88	1.49	0.006	1.12-1.97	1.46	0.009	1.10-1.95
>9	Ref			Ref			Ref		
Wait time (days)									
< 3				Ref			Ref		
≥ 3				1.85	<0.001	1.58-2.17	1.80	<0.001	1.53-2.11
Source of referral									
Home				Ref			Ref		
Acute/long-term care				0.66	<0.001	0.58-0.75	0.66	0.029	0.58-0.75
Length of stay (days)									
<15							Ref		
≥ 15							1.35	<0.001	1.21-1.50
Diagnosis									
Non-oncological							Ref		
Oncological							0.88	0.119	0.76-1.03

Legend: OR: Odd Ratio; CI: Confidence Interval.

Discussion

The aim of this study was to understand which factors affect SPCS utilization in terms of place of death and patient disenrollment from SPCS. An important result emerging from this study is that both predisposing and enabling factors (i.e. age, source of referral, wait time) were significantly associated with place of death and disenrollment, indicating that sociodemographic and healthcare organisational factors, not just patients' needs influence SPCS utilization.

Regarding place of death, consistent with previous studies (12,13,16,44), older age emerged as a predisposing factor significantly associated with home death. Younger individuals compared with older ones could have more severe symptomatology resulting in less management at home (14), mainly because in Italy younger patients are referred to SPCSs only in the very final stages of their disease progression (25).

This finding might also be related to a greater preference for home death expressed by the older compared to younger adults, as at home, the involvement of family members would be the highest. It is important to negotiate and then re-negotiate the goals of care during disease progression (45). Moreover, these findings show the importance of advanced care planning (ACP) in younger individuals affected by life-threatening diseases, and the need to start an open and timely discussion on their wishes and preferences.

Among the enabling factors, it emerged how individuals with a longer wait time for admission to SPCSs were more likely to die at home. Reasonably, patients

with a longer wait time could have less serious illnesses, so that the home setting was a suitable place to be cared for, from the beginning until death. Moreover, a longer wait time can be due to living arrangement, where family members need time to organise the home environment properly (46).

Place of death was also associated with source of referral. Individuals referred by hospitals or long-term care facilities had a trend to die in hospice. This result might be explained considering the severity of the illness and the social support that patients need during their illness (47). It is reasonable to assume that hospital physicians are more prone to enrol patients within residential hospices mainly because they represent a smoother transition with a higher level of patient/family acceptance. Furthermore, people coming from long-term care services can have a lack of family support, thus being cared for in their own home could be not possible (48).

Specific educational programmes for hospital physicians might help to better understand the potentiality of home specialist palliative care. Furthermore, palliative consultation before hospital discharge might support physicians when identifying the most appropriate palliative care setting for their patients. They might also feel safer in making this decision together with a palliative care specialist who could reassure the family members and make them feel more involved in healthcare decisions (49).

Needs factors associated with place of death were symptoms, diagnosis and survival time. Symptoms such as dyspnoea, consciousness disorder, and bowel/urinary dysfunction were clearly associated with hospice deaths. These results probably reflect a greater difficulty than family member encounters in managing complex physical symptoms, such as consciousness disorders and dyspnoea (50). Indeed, dyspnoea is often described as a sudden and difficult event to be managed at home, with the patients experiencing panic and fear of death (51). The association between oncological diagnosis and home as a place of death, consistent with previous studies (13,15,52), might indicate a higher level of competence achieved by palliative care teams in managing these kinds of patients at home until their death, while underlining the unpredictability of the trajectory of non-oncological disease, where symptoms and complications need to be managed in a safer place. Finally, in line with previous literature (5,18,53), this study showed that a longer survival time, considered as a proxy of lower disease severity, was associated with home death. This is an expected result and could be associated with more manageable symptoms which led to an increase in caregivers' confidence to provide adequate home care (54).

Disenrollment should be considered as a marker for case complexity and as an undesirable outcome (22) that makes patients more likely to die in acute care. Despite this issue, our study clearly showed that data on patients' disenrollment was lacking. This reflects the efforts made to analyse the phenomena around SPCS referral, in contrast to little research focused on what happens to those who leave palliative care service before dying.

With regards to the reasons for disenrollment, it is interesting to note that more than a quarter of patients disenrolled were transferred to acute care. This phenomenon may be related to an urgent discharge for a readily available service (i.e. emergency department), reinforcing the necessity to have a palliative care team available 24 hours/day and capable of providing care in person and in a timely manner, as well as to provide bedside care in case of crisis while supporting family members. Moreover, withdrawal to seek aggressive life-prolonging therapies may be related both to poorly negotiated palliative care transitions (55) and the beliefs and values of both patients and caregivers who emphasise longevity over death.

Among the predisposing factors, older patients were shown as less likely to be disenrolled from the SPCS, probably because they have less prognosis uncertainty resulting in fewer changes in preferences toward more aggressive treatment (19,46). Lower education was associated with SPCS disenrollment, and this result could be driven by a low health literacy level due to lacking education about health sensitive topics, leading up to a gap in knowledge about SPCSs and poor patient/caregiver awareness of their disease. These results are consistent with other studies (56-58).

The enabling factors analysed were both significant. Being referred from hospital or long-term facilities determined less disenrollment from SPCS, as if both patients and caregivers got used to being cared for by a specialised team. Patients with a longer wait time for SPCS admission were more likely to be disenrolled. A longer wait time may increase patient/family risk of ex-

periencing feelings of abandonment that may negatively affect their confidence in SPCSs. The latter aspect suggests reflecting on the importance of enhancing smooth and timely palliative care transitions with the aim of decreasing palliative service abandonment and reducing unnecessary palliative care.

Since the need factor 'length of stay' was also significantly associated with patient disenrollment, we might reasonably collocate a longer duration of wait admission and a longer length of stay due to an inappropriate SPCS referral or the patient becoming ineligible, which contributed significantly to a higher risk of being disenrolled and worsening outcomes (22). To overcome these problems, it is important to develop precise criteria/indicators to support healthcare providers in making decisions about when transition to SPCS should occur.

Conclusions

This study demonstrated that after referral to SPCSs, place of death and disenrollment are associated with several factors influencing SPCS utilization. Our results showed that factors such as age, wait time until admission, survival time, source of referral, symptoms and diagnosis might influence the place of death. Deep insight into those factors could guide healthcare professionals to tailor effective interventions to support patients and caregivers in their preferred place of care and death. Data on disenrollment identified some disenrollment risk factors (i.e. younger age, lower education, longer wait time for admittance and length of stay) of which every healthcare provider should be aware. In this regard, patients' health literacy may play an important role, and healthcare professionals should improve palliative care knowledge mainly in settings outside SPCSs to plan palliative care transitions smoothly. In summary, different factors—not just patient needs—were associated with place of death and disenrollment after referral to SPCSs. Further research is needed to define SPCS organisational strategies capable of supporting people to die in their place of choice consistent with their needs and preferences.

This manuscript includes some strengths that are noteworthy. First, we can assume that with the large sample included we gave a complete and realistic overview of the patient characteristics that can be associated with place of death, helping to complete the picture presented in international literature regarding this argument. Also, this manuscript sheds light on a poorly treated event such as disenrollment. Indeed, this is one of the few studies regarding this argument and these data can help health care professionals in identifying patients at risk of disenrollment and the appropriate time for patient enrolment in SPCS.

Some limitations must be considered. First, this study was conducted in a specific region of Italy. Considering the cultural implications, these results need to be contextualized to enhance their transferability in other contexts. Also, the retrospective design used administrative databases, limiting the types of factors that we could investigate, such as patient preferences. Finally, data were collected several years ago, hindering the relevance of the data for current practice and policy. Nevertheless, as the Italian health care policies and the related legislation has not changed since 2010 and considering the large sample, we view these results applicable in current practice.

References

1. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. N Engl J Med. 2013;368(13):1173-5.
2. Hui D, Bruera E. Models of integration of oncology and palliative care. Ann Palliat Med. 2015;4(3):89-98.
3. World Health Organization. Palliativecare for older people: better practices Copenhagen2011 [Available from: http://www.euro.who.int/__data/assets/pdf_file/0017/143153/

e95052.pdf.

4. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care. 2013;12:7.

5. Abe K, Miyawaki A, Kobayashi Y, Watanabe T, Tamiya N. Place of death associated with types of long-term care services near the end-of-life for home-dwelling older people in Japan: a pooled cross-sectional study. BMC Palliat Care. 2020;19(1):121.

6. Webber C, Hsu AT, Tanuseputro P, Fitzgibbon E, Li C. Acute Care Utilization and Place of Death among Patients Discharged from an Inpatient Palliative Care Unit. J Palliat Med. 2020;23(1):54-9.

7. 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.

8. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. J Palliat Med. 2000;3(3):287-300.

9. Cai J, Zhang L, Guerriere D, Fan H, Coyte PC. Where Do Cancer Patients in Receipt of Home-Based Palliative Care Prefer to Die and What Are the Determinants of a Preference for a Home Death? Int J Environ Res Public Health. 2020;18(1).

10. McCaughan D, Roman E, Smith AG, Garry AC, Johnson MJ, Patmore RD, et al. Perspectives of bereaved relatives of patients with haematological malignancies concerning preferred place of care and death: A qualitative study. Palliat Med. 2019;33(5):518-30.

11. Alawneh A, Anshasi H. Place of death for patients treated at a tertiary cancer center in Jordan. Support Care Cancer. 2020.

12. Sun Z, Guerriere DN, de Oliveira C, Coyte PC. Temporal trends in place of death for end-of-life patients: Evidence from Toronto, Canada. Health Soc Care Community. 2020;28(5):1807-16.

13. Tan WS, Bajpai R, Low CK, Ho AHY, Wu HY, Car J. Individual, clinical and system factors associated with the place of death: A linked national database study. PloS one. 2019;14(4):e0215566-e.

14. Stilwell P, Bhatt A, Mehta K, Carter B, Bisset M, Soanes L, et al. Preferred place of death in paediatric, teenage and young adult haemato-oncology patients: a retrospective review. BMJ Support Palliat Care. 2020.

15. 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 Res. 2020;40(7):3897-903.

16. Yeh S-T, Ng Y-Y, Wu S-C. Hospital and Patient Characteristics Regarding the Place of Death of Hospitalized Impending Death Patients: A Multilevel Analysis. Int J Environ Res Public Health. 2019;16(23):4609.

17. Carlson M, Herrin J, Du Q, Epstein AJ, Cherlin E, Morrison RS, et al. Hospice characteristics and the disenrollment of patients with cancer. Health Serv Res. 2009;44(6):2004-21.

18. Aldridge MD, Canavan M, Cherlin E, Bradley EH. Has Hospice Use Changed? 2000-2010 Utilization Patterns. Med Care. 2015;53(1):95-101.

19. Casarett DJ, Marenberg ME, Karlawish JH. Predictors of withdrawal from hospice. J Palliat Med. 2001;4(4):491-7.

20. Johnson KS, Kuchibhatla M, Tanis D, Tulsky JA. Racial differences in hospice revocation to pursue aggressive care. AMA Arch Intern Med. 2008;168(2):218-24.

21. Wang SY, Dang W, Aldridge MD, Canavan M, Cherlin E, Bradley E. Associations of Hospice Disenrollment and Hospitalization With Continuous Home Care Provision. Med Care. 2017;55(9):848-55.

22. Carlson M, Herrin J, Du Q, Epstein AJ, Barry CL, Morrison RS, et al. Impact of hospice disenrollment on health care use and medicare expenditures for patients with cancer. J Clin Oncol. 2010;28(28):4371-5.

23. Andersen R, Davidson PL. Improving Access to Care in America: Individual and Contextual Indicators. Changing the US health care system: Key issues in health services policy and management, 3rd ed. San Francisco, CA, US: Jossey-Bass; 2007. p. 3-31.

24. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol. 2008;61(4):344-9.

25. D'Angelo D, Di Nitto M, Giannarelli D, Croci I, Latina R, Marchetti A, et al. Inequity in palliative care service full utilisation among patients with advanced cancer: a retrospective Cohort study. Acta Oncol (Stockholm, Sweden). 2020;59(6):620-7.

26. Andersen R. Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav 1995;36(1):1-10.

27. Lee SH, Ryu JI, Jung SH. Differences in Utilization of Medical and Dental Services among Homeless People in South Korea. Int J Environ Res Public Health. 2020;17(15).

28. Serna CA, Sanchez J, Arevalo O, et al. Self-reported factors associated with dental care utilization among Hispanic migrant farmworkers in South Florida. J Public Health Dent. 2020;80(3):186-193.

29. Jönsson B, Holde GE, Baker SR. The role of psychosocial factors and treatment need in dental service use and oral health among adults in Norway. Community Dent Oral Epidemiol. 2020;48(3):215-24.

30. Li W, Dorstyn DS, Denson LA. Predictors of Mental Health Service Use by Young Adults: A Systematic Review. Psychiatr Serv (Washington, DC). 2016;67(9):946-56.

31. Phillipson L, Jones SC, Magee C. A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. Health Soc Care Community. 2014;22(1):1-12.

32. Roberts T, Miguel Esponda G, Krupchanka D, Shidhaye R, Patel V, Rathod S. Factors associated with health service utilisation for common mental disorders: a systematic review. BMC Psychiatry. 2018;18(1):262.

33. Franck JE, Ringa V, Cœuret-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(1):51-62.

34. Jin SW, Yun Lee H, Lee J. Analyzing factors enabling colorectal cancer screening adherence in Korean Americans using the Andersen's Behavioral Model of Health Services Utilization. J Psychosoc Oncol. 2019;37(6):729-45.

35. Lee HY, Lust K, Vang S, Desai J. Male Undergraduates' HPV Vaccination Behavior: Implications for Achieving HPV-Associated Cancer Equity. J Community Health. 2018;43(3):459-66.

36. Lindley LC. The Effect of Pediatric Palliative Care Policy on Hospice Utilization Among California Medicaid Beneficiaries. J Pain Symptom Manage. 2016;52(5):688-94.

37. Lindley LC, Newnam KM. Hospice Use for Infants With Life-Threatening Health Conditions, 2007 to 2010. J Pediatr Health Care. 2017;31(1):96-103.

38. Lindley LC, Shaw SL. Who are the children using hospice care? J Spec Pediatr Nurs. 2014;19(4):308-15.

39. Definizione degli standard relativi all'assistenza ai malati terminali in trattamento palliativo, in attuazione dell'articolo 1, comma 169, della legge 30 dicembre 2004, n. 311, (2007).

40. Ministry of health. <Rapporto al Parlamento sullo stato di attuazione della Legge n. 38 del 15 marzo 2010>. Rome: Italian Government; 2019.

41. Jordan RI, Allsop MJ, ElMokhallalati Y, Jackson CE, Edwards HL, Chapman EJ, et al. Duration of palliative care before death in international routine practice: a systematic review and meta-analysis. BMC Med. 2020;18(1):368.

42. Little RJA. A Test of Missing Completely at Random for Multivariate Data with Missing Values. J Am Stat Assoc. 1988;83(404):1198-202.

43. Blankers M, Koeter MW, Schippers GM. Missing data approaches in eHealth research: simulation study and a tutorial for nonmathematically inclined researchers. J Med Internet Res. 2010;12(5):e54.

44. Jarosek SL, Shippee TP, Virnig BA. Place of Death of Individuals with Terminal Cancer: New Insights from Medicare Hospice Place-of-Service Codes. J Am Geriatr Soc. 2016;64(9):1815-22.

45. Malhotra C, Bundoc FG, Sim D, Jauferally FR, Finkelstein EA. Instability in Preference for Place of Death Among Patients With Symptoms of Advanced Heart Failure. J Am Med Dir Assoc. 2021;22(2):349.e29-.e34.

46. Neergaard MA, Brunoe AH, Skorstengaard MH, Nielsen MK. What socio-economic factors determine place of death for people with life-limiting illness? A systematic review and appraisal of methodological rigour. Palliat Med. 2019;33(8):900-25.

47. Artico M, Piredda M, D'Angelo D, Di Nitto M, Giannarelli D, Marchetti A, et al. Palliative care organization and staffing models in residential hospices: Which makes the difference? Int J Nurs Stud. 2022;126:104135.

48. Gladstone JW, Dupuis SL, Wexler E. Changes in family involvement following a relative's move to a long-term care facility. Can J Aging. 2006;25(1):93-106.

49. Higginson IJ, Daveson BA, Morrison RS, Yi D, Meier D, Smith M, et al. Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. BMC Geriatr. 2017;17(1):271.

50. Malik FA, Gysels M, Higginson IJ. Living with breathlessness: a survey of caregivers of breathless patients with lung cancer or heart failure. Palliat Med. 2013;27(7):647-56.

51. Simon ST, Higginson IJ, Benalia H, Gysels M, Murtagh FE, Spicer J, et al. Episodes of breathlessness: types and patterns - a qualitative study exploring experiences of patients with advanced diseases. Palliat Med. 2013;27(6):524-32.

52. Costa V, Earle CC, Esplen MJ, Fowler R, Goldman R, Grossman D, et al. The determinants of home and nursing home death: a systematic review and meta-analysis. BMC Palliat Care. 2016;15:8.

53. Johnson L, Blew A, Schreier AM. Health Disparities in Hospice Utilization and Length of Stay in a Diverse Population With Lung Cancer. Am J Hosp Palliat Care. 2019;36(6):513-8.

54. Soroka JT, Froggatt K, Morris S. Family Caregivers' Confidence Caring for Relatives in Hospice Care at Home: An Exploratory Qualitative Study. Am J Hosp Palliat Care. 2018;35(12):1540-6.

55. D'Angelo D, Mastroianni C, Artico M, Biagioli V, Latina R, Guarda M, et al. Validity and reliability of the Palliative Care Transition Measure for Caregivers (PCTM-C). Palliat Support Care. 2018:1-6.

56. Shah S, Qaisar F, Azam I, Mansoor K. Perceptions, knowledge and attitudes towards the concept and approach of palliative care amongst caregivers: a cross-sectional survey in Karachi, Pakistan. BMC Palliat Care. 2020;19(1):180.

57. Benini F, Fabris M, Pace DS, Vernò V, Negro V, De Conno F, et al. Awareness, understanding and attitudes of Italians regarding palliative care. Ann Ist Super Sanita. 2011;47(3):253-9.

58. Westerlund C, Tishelman C, Benkel I, Fürst CJ, Molander U, Rasmussen BH, et al. Public awareness of palliative care in Sweden. Scand J Public Health. 2018;46(4):478-87.

Correspondence:
Received: 2 December 2022
Accepted: 4 April 2022
Michela Piredda, RN, PhD, Associate Professor
Research Unit Nursing Science,
Campus Bio-Medico di Roma University
Alvaro del Portillo, 21
00128, Rome, Italy
Phone: +39 388 846 8735
E-mail: m.piredda@unicampus.it
ORCID: 0000-0001-5998-476X