

RESEARCH ARTICLE

Are older long term care residents accurately prognosticated and consequently informed about their prognosis? Results from SHELTER study data in 5 European countries

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Abstract

Background

Informing residents in long term care facilities (LTCFs) about their prognosis can help them prepare for the end of life. This study aimed to examine which proportion of European LTCF residents, close to death, are accurately prognosticated and consequently informed about their prognosis; and to examine factors related to accurate prognostication and discussion of prognosis.

Methods

A subsample of SHELTER study data was used, consisting of: 500 residents from 5 European countries, who died within 6 months after their last assessment, and had a valid answer on the item 'End stage disease, 6 or fewer months to live'. This item was used to indicate whether an accurate prognosis was established and discussed with residents. Generalized estimating equations were used to examine factors related to establishment and discussion of accurate prognosis.

Results

86.4% of residents close to death did not receive an accurate prognosis. Residents with cancer; fatigue; dehydration; and normal mode of nutritional intake were more likely to have an accurate prognosis established and discussed. Accurate prognostication and prognosis

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discussion was less likely for residents who: had a diagnosis under 'other'; initiated interactions; and residents from Germany, Italy and the Netherlands.

Conclusions

The great majority of residents close to death did not receive an accurate prognosis. Prognostication tools might help clinicians to increase their prognostic accuracy and communication training might help to discuss prognosis with residents.

Introduction

When approaching the end of life, most older people suffer from chronic diseases which can make their care needs complex and sometimes admission to a long term care facility (LTCF) necessary [1]. Most residents receive care in the LTCF until their death, making end of life (EOL) care and planning for EOL care an important aspect of care in LTCFs [2].

Assessing residents' life expectancy can help health care professionals to timely start planning EOL care and to provide appropriate care for residents nearing the end of life. Many health organizations state the importance of good communication between patients and healthcare professionals on end of life issues, which includes information about prognosis [3]. Patients prefer to be asked about their preferences for discussing prognosis, before clinicians share this with them [2, 4].

Even though, interviews with older adults revealed that the majority wanted to discuss their prognosis with their clinician. Such information is important for them to prepare for death, make the most of life and to make medical decisions [2].

For persons with chronic diseases, which include LTCF residents, it is often difficult to reliably assess life expectancy because their disease course is not easily predictable near the end of life [5]. Therefore, physicians may be reluctant to establish and discuss a prognosis with patients [6, 7].

A study in French nursing homes showed that 63.5% of residents or their families were informed about the prognosis in the last months before death [8]. It is unknown whether this is comparable in other European countries. Also, the prognostic accuracy is unknown. In addition it is unclear which factors are associated with a lack of establishing and providing an accurate prognosis to LTCF residents.

Therefore this study aimed to: examine which proportion of long term care residents from 5 European countries, who are close to death, are accurately prognosticated and consequently informed about their prognosis; and to examine factors that are related to being accurately prognosticated and consequently informed about prognosis.

Methods

Research ethics approval for the SHELTER study was received for all participating countries and specifically from the following ethics committees: Medisch Ethische Toetsingscommissie VU Medisch Centrum; Comitato Etico, Universita Cattolica del Sacro Cuore Rome; Tutkimuseettinen Työryhmä, Terveystieteiden ja Hyvinvoinnin Laitos; Ethics Committee, University of Haifa; Ethikkommission der Universität Ulm; Multicentric Ethics Committee, General Faculty Hospital Prague; Ethics Committee Hospital Saint Péline Paris; School's Research Ethics

Committee, University of Kent Canterbury. Written consent was obtained with assurance of data confidentiality.

Study setting

The sample for this study was drawn from the Services and Health for Elderly in Long TERM-care (SHELTER) project, which was funded by the Seventh Framework Programme of the European Union [9]. This 12-month prospective cohort study involved seven European countries (Czech Republic, England, Finland, France, Germany, Italy, and the Netherlands) and one non-European country (Israel). In each country a sample of LTCFs willing to participate were identified. Therefore the sample was not randomly selected and not necessarily representative of all LTCFs in these countries. In total 57 LTCFs and 4156 LTCF residents were included.

The study was conducted from 2009 to 2011. Approval for the study was obtained in all participating countries, according to local ethical regulations.

The SHELTER project aimed to validate the interRAI LTCF in a European sample. The interRAI LTCF is a standardized instrument to assess care needs and care provision to LTCF residents. It contains over 350 items, such as: sociodemographic variables; physical, cognitive and psychosocial functioning; clinical diagnoses; treatments; and medication use.

In most facilities data was collected solely as research data and not as routine data. In those facilities data was collected by research nurses independent of the facility. All research nurses were trained for data collection according to the same procedure, which included use of a variety of information sources (personal interviews or observation, chart review and communication with (informal) care givers) to score items.

Older people living in participating LTCFs at the beginning of the study and those admitted in the 3 months enrolment period were assessed by the interRAI LTCF. Residents were then followed-up at 6 months and 12 months. No exclusion criteria were adopted. Residents were invited to participate in the study and were free to decline participation. Written consent was obtained with assurance of data confidentiality.

Sample

To answer the research questions, a subsample of the SHELTER study sample was selected. This subsample consisted of residents who were close to death: residents who died ≤ 6 months after their last assessment and who had a valid answer on the interRAI LTCF item 'End stage disease, 6 or fewer months to live'. Finland, France and Israel were excluded due to selective missing data on the time till death of the last assessment. The study sample comprised 500 residents from Czech Republic, Germany, Italy, the Netherlands and England.

Outcome measure

The item 'End stage disease, 6 or fewer months to live' was used as the outcome variable. This item indicates whether a resident is expected to live ≤ 6 months and also whether this has been communicated with the resident or family. This item was scored with either yes or no. As this study only included residents who actually had died ≤ 6 months after assessment, scoring 'no' was deemed as residents not being accurately prognosticated and consequently informed about prognosis. On the other hand, scoring yes meant that an accurate prognosis was established and provided to residents. Interrater reliability of this item was 0.6 in the SHELTER sample [9].

According to the interRAI LTCF manual, research nurses were instructed the following on scoring this item:

End-stage disease, 6 or fewer months to live: the person or family has been told that in the best clinical judgement of the physician, the person has end-stage disease with approximately 6 or fewer months to live. This judgement should be substantiated by a well-documented disease diagnosis and deteriorating clinical course.

Process: observe the person. Consult staff member, especially the person's physician. Review any clinical records. Use your clinical judgement to determine whether it is appropriate to ask the person about whether they have an 'end-stage disease' [10].

Independent variables

Independent variables assessed in this research included the following:

Sociodemographic variables: age; gender; and country.

Clinical diagnoses: dementia; other neurological disease; heart diseases; lung disease; infections; cancer; psychiatric disease; other; and number of comorbidities.

Functional status: Cognitive Performance Scale (CPS) (0 intact– 6 very severe impairment) [11]; Communication Scale (0 intact– 8 very severe impairment) [12]; Activities of Daily Living Hierarchy (ADLH) scale (0 no impairment– 6 total dependence) [13]; mode of nutritional intake (normal, impaired (any diet modification was necessary) or artificial (any type of feeding tube or parenteral nutrition was necessary); bladder incontinence (any degree of incontinence, catheter or ostomy present); and bowel incontinence (any degree of incontinence or ostomy device present).

Symptoms: Pain scale (0 no pain– 4 daily excruciating pain) [14]; fatigue (0 none– 4 unable to commence any normal day to day activities); Depression Rating Scale (DRS) (0–14, ≥ 3 , indicating depressive disorders) [15]; dyspnea (0 absent– 3 present at rest); anxiety (present, not present); time asleep during the day (awake all/most of the time—largely asleep/unresponsive); vomiting in last 3 days (present, not present); weight loss ($\geq 5\%$ in last 30 days / $\geq 10\%$ in last 180 days); dehydration / heightened BUN/Cre ratio; pressure ulcers (none—necrotic eschar).

Psychosocial functioning: pursues involvement in life of facility; initiates interactions with others; positive reaction to interactions initiated by others; adjusts easily to change in routine; average time involved in activities (most, more than two-thirds of the time; some, from one-third to two-thirds of the time; little, less than one-third of time; to none); feels lonely; experienced major life stressors in last 90 days; family or close friends reported feeling overwhelmed by resident's illness; consistent positive outlook; finds meaning in day-to-day life; and strong and supportive relationship with family.

Analysis

Frequencies and descriptives were used to describe the study sample and to indicate how many residents were accurately prognosticated and consequently informed about their prognosis.

Generalized estimating equations (GEE) were used to make a logistic regression model, in order to examine factors contributing to residents not being accurately prognosticated and informed about their prognosis. The item 'End stage disease, 6 or fewer months to live' was used as the dependent variable. GEE were used in order to adjust for the potential confounding effect of facility, as the data have a nested structure. Country was considered a factor that possibly contributed to the prediction model and was therefore treated as an independent variable in analyses. All GEE analyses were adjusted for the potential confounding effect of timing of the last assessment before death. Model specifications included an exchangeable correlation matrix and a robust covariance matrix estimator.

A forward selection strategy was used to make a prediction model. First univariate analyses were conducted. Because of the large amount of variables, only variables with a p-value <0.1 in univariate analysis were considered for the forward selection procedure. In the prediction model, p-values <0.05 were considered statistically significant. A minimum of 5 cases per parameter added to the prediction model was used as a rule of thumb to estimate the maximum amount of parameters in the model [16].

Continuous or scale variables that did not show a linear relation with 'End stage disease', were dichotomized. Odds ratios (OR) and 95% confidence intervals were derived from each analyses.

All analyses were conducted using IBM SPSS Statistics 22 for Windows (IBM SPSS Statistics, IBM Corporation, Chicago, IL).

Results

The mean age of residents on their last assessment was 84.7 (SD 8.8) years and 352 residents (70.4%) were women. The 500 residents were from Czech Republic (n = 142), Germany (n = 98), England (n = 150), Italy (n = 33), and the Netherlands (n = 77).

Proportion of LTCF residents that were accurately prognosticated and consequently informed about prognosis

Overall, 86.4% of residents were not accurately prognosticated and informed about their prognosis (Fig 1). This proportion was highest in Germany (98.0%) and lowest in England (79.3%). Generally as residents were closer to death, an accurate prognosis was more often established and provided (Fig 2). Of residents with an assessment less than a month before death 32.1% were accurately prognosticated and informed, which was significantly more often compared to residents one to six months before death ($p < 0.01$).

Factors related to LTCF residents not being accurately prognosticated and consequently informed about prognosis

Univariate analysis showed 19 variables with a p-value <0.1 (see Tables 1–3). Residents with: infections; cancer; cognitive, communication or ADL impairment; artificial or impaired nutritional intake; fatigue; weight loss; dehydration; overwhelmed friends or family; or major life stressors were more likely to be accurately prognosticated and consequently informed about their prognosis.

On the other hand, residents who: had a clinical diagnosis categorized under 'other'; pursued involvement; spent time involved in activities; initiated or reacted positively to interactions; adjusted easily to changes; had a consistent positive outlook on life; found meaning in life; or lived in the Netherlands, Germany or Czech Republic, were less likely to have an accurate prognosis established and shared with them.

The multivariate model (see Table 4) showed that residents with cancer, fatigue, dehydration, or an impaired or artificial mode of nutritional intake, were more likely to be accurately prognosticated and informed about their prognosis. However, the establishment and provision of an accurate prognosis was less likely for residents from Germany, the Netherlands or Italy and residents who had a diagnosis under 'other' or initiated interactions.

Discussion

First, results from this study showed that the great majority, namely 86.4%, of LTCF residents, seem not to be accurately prognosticated and consequently informed about their prognosis

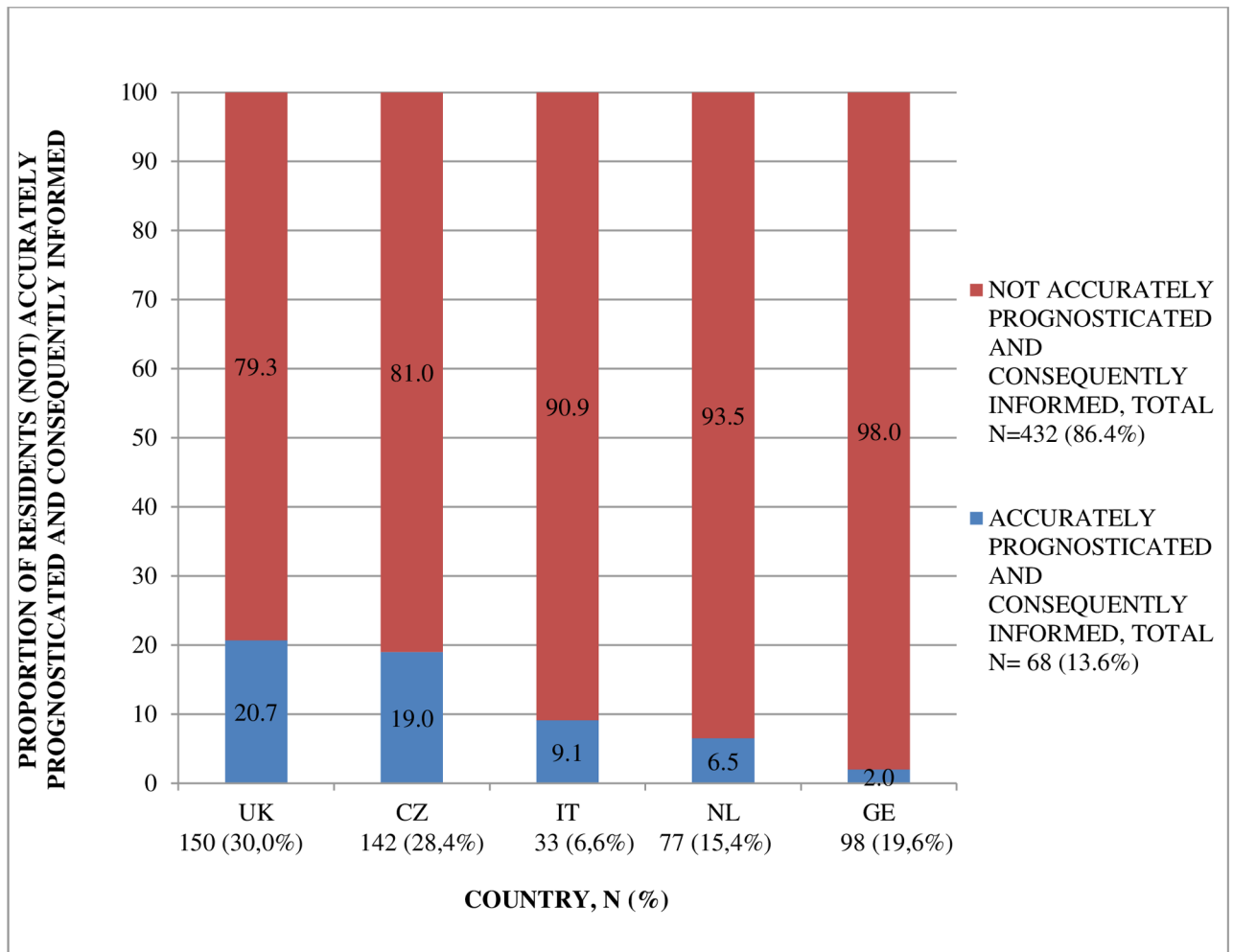


Fig 1. Proportion of residents (not) accurately prognosticated and consequently informed about their prognosis, per country.

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within 6 months of actual death. Second, residents with: cancer, fatigue, dehydration, or impaired of artificial mode of nutritional intake were more likely to be accurately prognosticated and informed. While residents who initiated interactions, had a diagnosis under ‘other’ or lived in a LTCF in Germany, the Netherlands or Italy were less likely accurately prognosticated and informed.

Proportion of LTCF residents that were accurately prognosticated and consequently informed about prognosis

Compared to the study conducted in French LTCFs, where 63.5% of residents or families were informed about the prognosis, the proportion of informed residents in this study seems quite low. A study in patients in general practice also showed higher proportions of life expectancy discussions: 23% and 68% of patients in Italy and the Netherlands, respectively [17].

A possible explanation for these differences could be that aforementioned studies only measured whether patients were informed about their prognosis. While the current study also questioned the accuracy of a more specific prognosis, namely ≤ 6 months to live. Thus scoring negatively on this item could entail several scenarios: a resident was neither prognosticated,

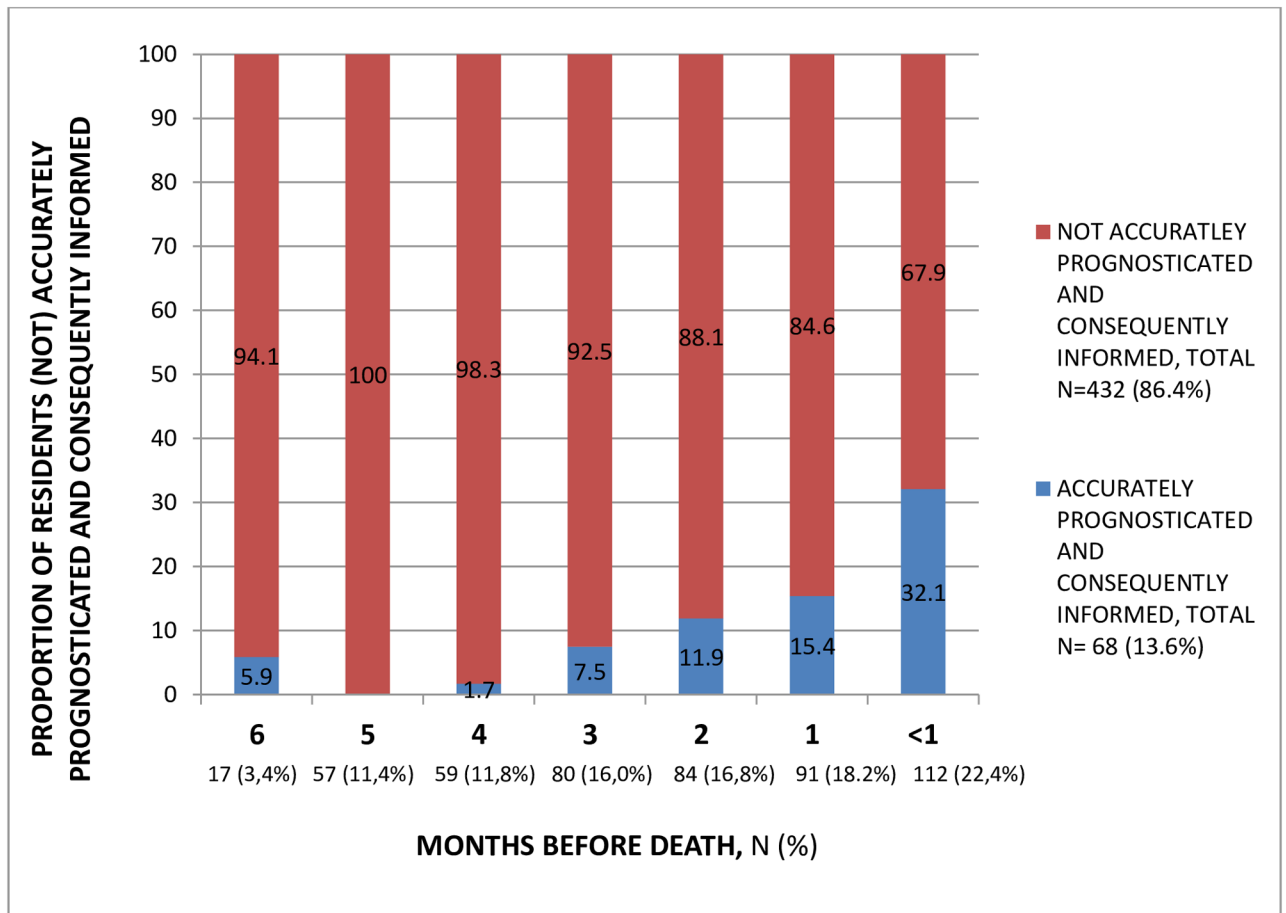


Fig 2. Proportion of residents (not) accurately prognosticated and consequently informed about their prognosis, according to months before death.

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nor informed about a prognosis; a resident was prognosticated, but not informed about this prognosis; or a resident had been informed about prognosis in more general terms, instead of specifying to ≤ 6 months to live. Clinicians have indicated to deal with prognostic uncertainty and rather not use too definitive or descriptive time frames [18]. Furthermore health professionals can feel uncomfortable to discuss prognosis with patients and be afraid it will have negative consequences for the patients [18]. Thus combining prognostication and discussing prognosis, both considered difficult, could have led to the low proportion found in this study.

Furthermore, in the current study the discussion of prognosis was preferably recorded prior to residents' deaths, while the other studies used retrospective surveys after patients had died. As discussing prognosis with patients is considered desirable [3], not having had such discussions with patients who died, could imply one has not delivered optimal care. Possibly retrospectively filling in whether prognosis was discussed leads to a higher degree of socially desirable answers and thus an overestimation. In the current study residents with an assessment < 1 month before death, were significantly more often prognosticated and informed about their prognosis than residents with an assessment 1–6 months before death. Research in nursing home residents with dementia has shown that as residents got closer to death, there was a significant increase of setting palliative care goals [19]. However, < 1 month before death still only less than 1/3 of residents received an accurate prognosis, indicating that physicians in

Table 1. Associations between sociodemographic characteristics, diagnoses and aspects of functional status and residents being accurately prognosticated and consequently informed, in univariate analyses.

		Resident accurately prognosticated and consequently informed				Univariate OR (95% CI) ^a	P-value
		Yes n = 68 (13.6%)		No n = 432 (86.4%)			
Sociodemographic characteristics							
Gender	Male	20	13.5%	128	86.5%		
	Female	48	13.6%	304	86.4%	1.24 (0.60–2.55)	.558
Age	≤85	40	16.3%	205	83.7%		
	>85	28	11.0%	227	89.0%	0.77 (0.48–1.23)	.274
Country	UK	31	20.7%	119	79.3%		
	NL	5	6.5%	72	93.5%	0.16 (0.05–0.58)	.005
	IT	3	9.1%	30	90.9%	0.59 (0.14–2.40)	.456
	CZ	27	19.0%	115	81.0%	0.39 (0.13–1.13)	.083
	GE	2	2.0%	96	98.0%	0.08 (0.02–0.25)	<.001
Diagnosis present							
Dementia	No	38	15.0%	215	85.0%		
	Yes	30	12.1%	217	87.9%	0.90 (0.50–1.61)	.714
Other neurological disease	No	43	13.5%	275	86.5%		
	Yes	25	13.7%	157	86.3%	1.00 (0.52–1.75)	.998
Heart disease	No	41	15.2%	228	84.8%		
	Yes	27	11.7%	204	88.3%	0.69 (0.33–1.43)	.313
Lung disease	No	58	13.2%	383	86.8%		
	Yes	10	16.9%	49	83.1%	1.13 (0.57–2.26)	.725
Infections	No	52	11.8%	389	88.2%		
	Yes	16	27.1%	43	72.9%	1.61 (0.79–3.25)	.188
Cancer ^b	No	34	8.4%	369	91.6%		
	Yes	34	35.4%	62	64.6%	5.22 (2.71–10.06)	<.001
Psychiatric disease	No	51	13.1%	339	86.9%		
	Yes	17	15.5%	93	84.5%	1.32 (0.64–2.73)	.451
Other diagnosis	No	53	14.8%	53	14.8%		
	Yes	15	10.6%	127	89.4%	0.50 (0.28–0.89)	.019
No. of comorbidities	≤4	36	12.5%	253	87.5%		
	(>4)	32	15.2%	179	84.8%	1.07 (0.66–1.75)	.787
Aspects of functional status							
Cognitive function	Intact—mild impairment	21	10.4%	181	89.6%		
	Moderate-severe impairment	47	15.8%	251	84.2%	1.77 (1.05–2.99)	.033
Communication	Intact-mild impairment	23	10.4%	199	89.6%		
	Moderate-very severe impairment	45	16.2%	233	83.8%	1.75 (1.15–2.67)	.009
ADL	Independent-limited impairment	5	5.6%	85	94.4%		
	Extensive assistance- total dependence	63	15.4%	347	84.6%	2.29 (1.13–4.64)	.022
Nutritional intake ^b	Normal	16	6.8%	221	93.2%		
	Impaired	42	18.1%	190	81.9%	2.10 (1.15–3.84)	.015
	Artificial feeding	9	30.0%	21	70.0%	2.84 (1.11–7.29)	.030
Bladder incontinence	No	7	11.1%	56	88.9%		
	Yes	61	14.0%	376	86.0%	1.08 (0.50–2.32)	.843

(Continued)

Table 1. (Continued)

		Resident accurately prognosticated and consequently informed				Univariate OR (95% CI) ^a	P-value
		Yes n = 68 (13.6%)		No n = 432 (86.4%)			
Bowel incontinence ^b	No	12	9.0%	121	91.0%	1.52 (.81–2.83)	.192
	Yes	52	14.4%	310	85.6%		

^aLogistic regression analyses using Generalised Estimating Equations. Dependent variable: 0 –not correctly classified as having 6 months or less to live, 1 –correctly classified as having 6 months or less to live. Adjusted for time till death.

^bNo. of missing values: Cancer, Nutritional intake: 1; Bowel incontinence: 5

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the LTCF setting probably have trouble establishing a prognosis, even when residents are nearing death. Possibly residents in the current study were prognosticated and informed about their prognosis in the period between assessment and actual death. Therefore the current study could underestimate actual practice.

As establishing a prognosis is important for clinicians to provide appropriate care and sharing this prognosis is important for patients, recommendations for practice should include both prognostication and communication with patients. Several tools have been developed

Table 2. Associations between residents’ symptom status and residents being accurately prognosticated and consequently informed, in univariate analyses.

		Resident accurately prognosticated and consequently informed				Univariate OR (95% CI) ^a	P-value
		Yes n = 68 (13.6%)		No n = 432 (86.4%)			
Pain	No	30	10.6%	253	89.4%	1.59 (0.75–3.36)	.225
	Yes	38	17.5%	179	82.5%		
Fatigue	No	18	6.5%	260	93.5%	3.05 (1.89–4.92)	<.001
	Yes	50	22.5%	172	77.5%		
Depression	No	43	12.3%	307	87.7%	1.51 (0.88–2.59)	.135
	Yes	25	16.7%	125	83.3%		
Dyspnoea	No	49	12.2%	352	87.8%	1.42 (0.87–2.31)	.164
	Yes	19	19.2%	80	80.8%		
Anxiety	No	60	13.1%	398	86.9%	1.55 (0.60–3.97)	.366
	Yes	8	19.0%	34	81.0%		
Time sleep during the day	Awake all/most time	14	8.4%	153	91.6%	1.47 (0.86–2.52)	.162
	Multiple naps—largely asleep	54	16.2%	279	83.8%		
Vomiting	No	61	13.0%	410	87.0%	2.01 (0.82–4.90)	.127
	Yes	7	24.1%	22	75.9%		
Weight loss	No	38	9.5%	360	90.5%	2.72 (1.53–4.84)	.001
	Yes	30	29.4%	72	70.6%		
Pressure ulcer	No	45	11.1%	360	88.9%	1.61 (0.90–2.91)	.110
	Yes	23	24.2%	72	75.8%		
Dehydrated ^b	No	51	10.9%	419	89.1%	9.97 (3.60–27.64)	<.001
	Yes	17	58.6%	12	41.4%		

^aLogistic regression analyses using Generalised Estimating Equations. Dependent variable: 0 –not correctly classified as having 6 months or less to live, 1 –correctly classified as having 6 months or less to live. Adjusted for time till death.

^bNo. of missing values: Dehydrated: 1.

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Table 3. Associations between psychosocial characteristics of residents and residents being accurately prognosticated and consequently informed, in univariate analyses.

		Resident accurately prognosticated and consequently informed				Univariate OR (95% CI) ^a	P-value
		Yes n = 68 (13.6%)		No n = 432 (86.4%)			
Pursues involvement ^b	No	50	17.4%	237	82.6%	0.40 (0.23–0.71)	.002
	Yes	15	7.2%	192	92.8%		
Initiates interactions ^b	No	51	16.8%	252	83.2%	0.38 (0.21–0.67)	.001
	Yes	14	7.3%	177	92.7%		
Reacts positively to interactions ^b	No	29	18.2%	130	81.8%	0.60 (0.34–1.06)	.078
	Yes	36	10.7%	299	89.3%		
Adjusts easily to change in routine ^b	No	40	16.5%	202	83.5%	0.63 (0.39–1.02)	.061
	Yes	25	9.9%	227	90.1%		
Time involved in activities (some—most involvement) ^b	No	55	18.0%	250	82.0%	0.52 (0.28–0.97)	.041
	Yes	13	6.7%	181	93.3%		
Family overwhelmed ^b	No	45	10.8%	373	89.2%	2.54 (1.20–5.35)	.014
	Yes	20	26.3%	56	73.7%		
Lonely ^b	No	47	11.2%	372	88.8%	1.99 (0.75–5.25)	.165
	Yes	18	24.0%	57	76.0%		
Major life stress ^b	No	42	10.4%	360	89.6%	1.97 (0.95–4.10)	.069
	Yes	23	25.0%	69	75.0%		
Consistent positive outlook ^b	No	48	16.1%	250	83.9%	0.56 (0.33–0.97)	.037
	Yes	17	8.7%	179	91.3%		
Finds meaning ^b	No	50	18.7%	217	81.3%	0.32 (0.17–0.59)	<.001
	Yes	15	6.6%	212	93.4%		
Strong relationship with family ^b	No	23	13.9%	142	86.1%	0.79 (0.44–1.41)	.417
	Yes	42	12.8%	287	87.2%		

^aLogistic regression analyses using Generalised Estimating Equations. Dependent variable: 0 –not correctly classified as having 6 months or less to live, 1 –correctly classified as having 6 months or less to live. Adjusted for time till death.

^bNo. of missing values: Pursues involvement, initiates interactions, reacts positively to interactions, adjusts easily to change in routine, family overwhelmed, lonely, major life stress, consistent positive outlook, finds meaning, strong relationship with family: 6; Time involved in activities: 1

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which can aid clinicians in estimating life expectancy of LTCF residents [20–24]. Communication training has shown to improve clinicians communication skills [25] and could perhaps improve discussing prognosis with residents. A starting point for this training could be the following key elements of discussing prognosis: establish what the patient and family already know about their prognosis; determine whether the patient is ready to discuss prognosis and what the patients wants to know; deliver information clearly; and respond appropriately to a patient’s emotion [26].

Factors related to LTCF residents not being accurately prognosticated and consequently informed about prognosis

Residents who had cancer were more often prognosticated and informed about their prognosis, while this was less often for residents with a diagnosis under ‘other’. This is concurrent with literature, as cancer patients usually have a more predictable illness trajectory and are easier to prognosticate, they tend to receive more end-of-life information [5, 8, 17, 27].

Table 4. Factors related to residents not being accurately prognosticated and consequently informed, in multivariate analyses.

		Multivariate OR (95% CI) ^a	P-value
Country	UK		
	NL	0.25 (0.11–0.58)	.001
	IT	0.18 (0.05–0.66)	.009
	CZ	0.47 (0.17–1.28)	.138
	GE	0.06 (0.01–0.34)	.001
Cancer	No		<.001
	Yes	11.04 (5.34–22.83)	
Mode of nutritional intake ^b	Normal		
	Impaired	2.02 (0.94–4.33)	.073
	Artificial feeding	6.80 (2.17–21.36)	.001
Fatigue	No		.002
	Yes	2.73 (1.45–5.14)	
Dehydrated	No		<.001
	Yes	8.16 (2.52–26.48)	
Diagnosis other	No		.024
	Yes	0.52 (0.29–0.92)	
Initiates interactions	No		.022
	Yes	0.44 (0.22–0.89)	

^a Multivariate logistic regression analyses using Generalised Estimating Equations. A forward selection approach was used, entering only variables with $p < 0.1$ in univariate analyses and using $p < 0.05$ as a cut-off point in the multivariate model. $N = 492$. Dependent variable: 0 –not correctly classified as having 6 months or less to live, 1 –correctly classified as having 6 months or less to live. Adjusted for time till death.

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Furthermore, studies have shown that fatigue, dehydration and artificial or impaired mode of nutritional intake are predictive of mortality in LTCF residents [21, 24, 28, 29]. Thus according to literature, a resident presenting with these factors would indeed represent a resident who is closer to death. This could explain why these residents were more often accurately prognosticated and informed about their life expectancy in the current study.

On the other hand, prognosis was less often accurately established and discussed with residents who still initiated interactions. Possibly clinicians think that these residents are so much engaged in life that they are not ready yet to discuss end-of-life matters and clinicians fear it will have negative consequences. Navigating patient’s readiness and fear of causing distress are known barriers for clinicians in end-of-life communication [30, 31]. However, patients can still enjoy a good quality of life and acknowledge their prognosis [32].

Country of residence was also related to whether or not physicians would establish and discuss prognosis with residents. Differences between countries were also seen in the intention to discuss prognosis with patients [33] and in GPs discussing prognosis [17]. As in general practice, possibly country specific differences in health service organisation and the importance of autonomy could play a role in these differences found between countries [17].

Strengths and limitations

This is the first study on establishing and discussing prognosis in LTCFs, that used data from several European countries. To our knowledge it was also the first prospective study on this subject. The extensive SHELTER database made it possible to consider an array of factors that might be related to a lack of establishing and discussing prognosis.

Another strength of this study is using forward selection to build the model. The number of parameters that could be entered in a regression model was limited, since only 68 residents scored 'yes' on the outcome variable. Backward selection would have required a rigorous pre-selection of the many variables that were considered, making the analysis less transparent.

A limitation of the item 'End stage disease, 6 or fewer months to live', is the impossibility to distinguish between residents who were: prognosticated but not informed on their prognosis; informed about their prognosis but not specifically using a 6-month time window; and not prognosticated and informed about prognosis at all. All these residents would not be scored affirmatively on this interRAI item, but for different reasons the current study cannot differentiate between.

Another limitation that should be mentioned, is the relatively small number of residents from Italy, compared to the samples from the other countries. Cross-country comparisons with Italy and implications from the Italian data, should therefore be interpreted with caution.

Conclusion

The great majority of LTCF residents who were close to death, were not accurately prognosticated and consequently informed about their prognosis in the current study. While residents closer to death were more often informed about their life expectancy, most residents assessed <1 month before death still did not receive an accurate prognosis. Prognostication tools might help clinicians to increase their prognostic accuracy and communication training might help to discuss prognosis with residents. Future studies might investigate whether residents are perhaps being informed about their prognosis in more general terms early in the disease trajectory and whether prognosis is being updated as a resident's condition deteriorates. As it is currently not clear whether most difficulties lie with prognostication or with discussing this with residents, future research could distinguish between these matters.

Supporting information

S1 Dataset.
(SAV)

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