Palliative Medicine

Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study

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Abstract

Background: Of deaths in high-income countries, 75% are caused by progressive advanced chronic conditions. Palliative care needs to be extended from terminal cancer to these patients. However, direct measurement of the prevalence of people in need of palliative care in the population has not been attempted.

Aim: Determine, by direct measurement, the prevalence of people in need of palliative care among advanced chronically ill patients in a whole geographic population.

Design: Cross-sectional, population-based study. Main outcome measure: prevalence of advanced chronically ill patients in need of palliative care according to the NECPAL CCOMS-ICO© tool. NECPAL+ patients were considered as in need of palliative care.

Setting/participants: County of Osona, Catalonia, Spain (156,807 inhabitants, 21.4% > 65 years). Three randomly selected primary care centres (51,595 inhabitants, 32.9% of County's population) and one district general hospital, one social-health centre and four nursing homes serving the patients. Subjects were all patients attending participating settings between November 2010 and October 2011.

Results: A total of 785 patients (1.5% of study population) were NECPAL+: mean age = 81.4 years; 61.4% female. Main disease/condition: 31.3% advanced frailty, 23.4% dementia, 12.9% cancer (ratio of cancer/non-cancer = 1/7), 66.8% living at home and 19.7% in nursing home; only 15.5% previously identified as requiring palliative care; general clinical indicators of severity and progression present in 94% of cases.

Conclusions: Direct measurement of prevalence of palliative care needs on a population basis is feasible. Early identification and prevalence determination of these patients is likely to be the cornerstone of palliative care public health policies.

Keywords

Palliative care, chronic disease, frail elderly, prevalence, health planning, public health

Introduction

Background

Currently, the predominant model of palliative care (PC) focuses on terminal cancer. However, specialist PC services need to be extended to all patients with any kind of advanced chronic conditions with a progressive clinical trajectory, often with frequent crises,[1,2] to improve their quality of life in any setting of care.[3] Policymakers and managers have growing concerns regarding the rise in chronically ill patients with their attendant burden of need, demands of care and resource use.[4–8] Defining the prevalence of the problem is essential in generating public health-oriented PC planning.

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What is already known about the topic?

- Estimation of palliative care needs on a population basis using death registration or other indirect data
- Mortality due to chronic diseases

What this paper adds?

- New and prospective direct method of measuring – as opposed to estimating – prevalence of palliative care needs on a population basis
- Determination, by direct measurement, of the prevalence of people in need of palliative care in a whole geographic region, being 1.5% of the population
- Prevalence of palliative care needs mainly attributable to advanced frailty and general clinical indicators of severity and progression, irrespective of individual conditions

Implications for practice, theory or policy

- Determination of the prevalence of patients with advanced chronic conditions and limited life prognosis must be the first step when designing palliative care public health policies
- Health systems require to perform a significant shift in thinking with regard to care of most of advanced chronic patients with limited life prognosis from an institutional towards a community-oriented approach

Assessing PC needs in a population can be determined by several methods.[9–12] In high-income countries, around 75% of the population die due to chronic conditions, with the ratio of cancer to non-cancer deaths of about 1:2.[13,14] Such evidence has been estimated using death registration or other indirect data.[15] Direct measurement of the prevalence of PC needs in the population has not been attempted.

Several tools have been developed to identify patients likely to die within a very short period, applied in various settings and to different individual diseases.[16–21] The Prognostic Indicator Guidance (PIG)[22] was the first instrument to attempt this identification in a community-based setting, and has inspired similar tools[23,24] for use in different settings such as primary care centres, hospitals and nursing homes (NHs).[25–29] The NECPAL CCOMS-ICO© tool (NECesidades PALiativas Centro Colaborador de la Organización Mundial de la Salud – Institut Català d'Oncologia, in Spanish; Palliative Needs World Health Organization Collaborating Centre – Catalan Institute of Oncology, in English) has been developed to identify people in need of PC. It is based on similar British instruments[22,23] and is currently content-validated in the Spanish cultural and clinical context.[30]

A comprehensive PC programme has been implemented in Catalonia (Spain) since 1990.[31,32] To address current challenges in PC provision, a new comprehensive programme named NECPAL has recently been designed and implemented jointly by the World Health Organization (WHO) Collaborating Centre for Palliative Care Public Health Programmes and the Catalan Department of Health.[33] Direct measurement of the prevalence of PC needs in the population is proposed.

Objectives

We sought to determine the prevalence, by direct measurement, of advanced chronically ill patients with limited life prognosis in need of PC in a population identified by health-care professionals using the NECPAL CCOMS-ICO© tool. Furthermore, the report describes the main characteristics and care settings of these patients.

Methods

Study design

This is a cross-sectional, population-based study identifying those patients with advanced chronic diseases, limited life prognosis and PC needs as assessed using the NECPAL CCOMS-ICO© tool by health-care professionals.

Setting

The County of Osona is 1260 km^2 in area, located north of Barcelona in the Autonomous Region of Catalonia (Spain). It is a mixed urban–rural district with an overall population of 156,807 inhabitants, 21.4% of whom are aged >65 years. The annual mortality rate is 8.81 per 1000 inhabitants. It has a complete range of health and social care resources, including 11 primary care centres; 1 district general hospital (DGH) with 210 beds; 2 social-health centres (SHCs) which provide rehabilitation, PC, long-term care and dementia facilities; and 22 NHs with a total of 1178 beds. It also has a comprehensive organisational system for geriatric, dementia, palliative and chronic care across all settings formally coordinated and linked by a common computerised information system. Care is publicly funded within the
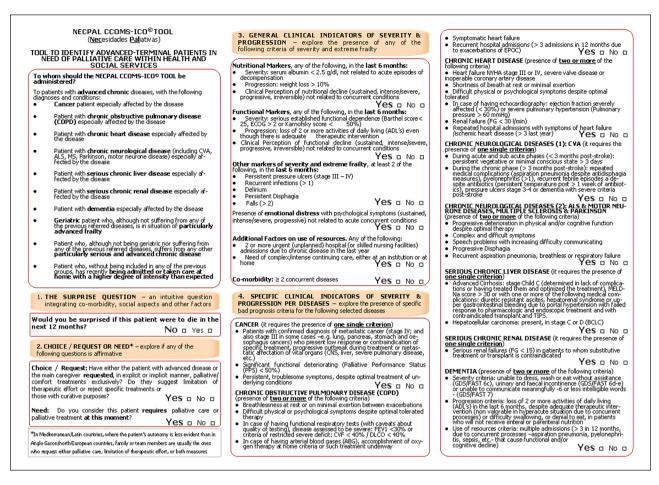
Figure 1. The NECPAL CCOMS-ICO© tool.

National Health System (NHS) and is free at the point of access. All patients are registered to one of the primary care centres.

The primary care centres of the County were classified as rural, rural–urban and urban areas. Once stratified, one primary care centre from each stratum was randomly selected by using a lottery system, and invited to participate. Other settings included in the study were the DGH, and all four NHs and the one SHC serving these three primary care centres. Outpatient clinics, day care facilities and day hospitals were excluded on the assumption that patients would be identified in primary care centres. All invited services agreed to participate.

Participants

Case selection was undertaken in the period of November 2010 to October 2011. A list of patients suffering from advanced chronic conditions was generated using primary care clinical risk groups (CRGs),[34] patients in home care programme and lists of patients with any of the eight selected most prevalent conditions[14] (cancer, chronic

obstructive pulmonary disease, chronic heart disease, chronic neurological disease (either vascular or degenerative), serious chronic liver disease, serious chronic renal disease, dementia and advanced frailty), as well as any other advanced condition, chronic or not (Figure 1). In inpatient settings, case identification was made from lists of admitted patients. From these lists, doctor and nurse were asked to select (individually and in combination) all possible advanced chronically ill patients. Agreement between doctors and nurses was not required for a case to be accepted to the list.

Data collection

To determine the prevalence of people in need of PC from among those identified as having advanced chronic conditions, we used the Catalan version of the NECPAL CCOMS-ICO© tool (Figure 1),[35] which has four categories: (1) the 'surprise question'; (2) choice/demand or need of PC approach; (3) general clinical indicators of severity and progression, including co-morbidity and resource use; and (4) disease-specific indicators.

For category 3, functional and nutritional decline was defined as progressive, sustained, not related to an acute event in the last 6 months, and assessed by clinical judgement.

All quantitative variables of the NECPAL CCOMS-ICO© tool were retrieved, if available, from patient's clinical records by the investigating team after interview with health-care professionals to respond to categories 1 and 2, and indicators to be answered by clinical judgement in category 3.

We categorised the patient as surprise question positive (SQ+), when the attending health-care professionals' answer was 'no' (i.e. 'No, I would not be surprised if this patient were to die in the next 12 months'). NECPAL+ patients were defined as being SQ+, plus having at least one positive category from among the remaining ones. NECPAL+ patients were considered as in need of PC.

In order to reduce systematic error, all definitions, procedures and measures were standardised and followed according to the study operations manual; all people involved in collecting data were trained to gather data according to standardised methodology, and collectors of quantitative data were blinded regarding patients' surprise question condition.

Statistical analysis

Population prevalence

The prevalence in each of the three categories (identified cases of advanced chronic disease, SQ+ and NECPAL+ cases) was determined based on census data of the County of Osona using the population served by participating primary care centres as the denominator. The numerator included patients registered in primary care centres, as well as those who were inpatients at DGH, SHC and NH at the time of data collection. When patients were identified in different settings within the data collection period, they were counted as single cases as patients of the primary care centres.

Prevalence in inpatient facilities

Additionally, we calculated the prevalence within DGH, SHC and NH individually using as denominator the total number of registered patients present in each setting, regardless of place of residence, and also for each individual general practitioner (GP). Absolute numbers and percentages by age, gender, disease/condition and setting groups were calculated for these three categories of patients. The package used for statistical analyses of the data was STATA v11 for Windows.

Ethical oversight

This study was formally approved by the ethical research committees of institutions involved in its execution (2010/PREVOsona: P10/65 and EO65).

Results

Participating primary care centres were rural centre ($n = 10,081$), rural–urban centre ($n = 17,529$) and urban centre ($n = 23,985$). Total study population was 51,595 (32.9% of the County's total population).

A total number of 1064 patients were identified as having advanced chronic conditions: 731 resident in the community, 204 in NHs, 74 at the SHC and 55 at the DGH. The population and settings prevalence are shown in Tables 1 and 2. Of the study population, 1064 (2.1%) were identified as having an advanced chronic disease, 841 (1.6%) were SQ+ and 785 (1.5%) were NECPAL+. In the population aged >65 years, these proportions increased to 10.9%, 8.6% and 8.0%, respectively. The vast majority of NECPAL+ patients were at home (66.8%) or in NH (19.7%). The mean prevalence of NECPAL+ patients/GP was 18.

The characteristics and distributions of patients by age, gender and clinical condition are shown in Table 3. Among NECPAL+ patients, almost two-thirds were female, the mean age was 81 years (minimum 16 and maximum 103 years), with only 9% <65 and 67.5% ≥80 years of age. The most frequent conditions were advanced frailty and dementia, followed by cancer. The ratio of cancer to non-cancer patients was 1:7.

Table 4 describes the characteristics of NECPAL+ patients segregated by setting and disease/condition. Significant differences were found regarding gender, age and clinical conditions distribution.

The prevalence of NECPAL CCOMS-ICO© tool criteria among identified cases of advanced chronic disease, SQ+ and NECPAL+ patients is shown in Table 5. The most frequent parameters among the three groups, accounting for more than 85% of cases, were in category 3 (general clinical indicators of severity and progression).

Among NECPAL+ patients, choice/demand of PC or limitations to the use of major therapeutic interventions was requested by 26.6% of carers and 5.6% of patients, while health-care professionals identified need of PC approach in 15.5% of them.

Co-morbidity (identified by Charlson index ≥ 2), functional decline, loss of two activities of daily life, nutritional decline, demand from primary carers for PC, severe emotional distress, increase in nursing care need, confusion syndrome, PC needs identified by professionals and severe dependency (Barthel index < 20) were the most frequent NECPAL CCOMS-ICO© tool indicators observed.

Concordance between doctor and nurse assessments

There was agreement of 76.9% of cases between doctors and nurses in the identification of SQ+ patients, which is a moderate degree of concordance (kappa = 0.4776; $p < 0.001$)

Table 1. Population prevalence of advanced chronically ill, SQ+ and NECPAL+ patients (51,595 inhabitants) and distribution of recruitment by settings.

	Advanced chronically ill, n (%)	SQ+, n (%)	NECPAL+, n (%)
Population	1064 (2.06)	841 (1.63)	785 (1.52)
Primary care	731 (68.7)	557 (66.2)	524 (66.8)
Nursing home	204 (19.2)	177 (21.0)	155 (19.7)
Social-health centre	74 (7.0)	55 (6.5)	55 (7.0)
District general hospital	55 (5.2)	52 (6.2)	51 (6.5)

SQ+: surprise question positive; NECPAL+: patients being SQ+, plus having at least one positive category from among the four categories of the NECPAL CCOMS-ICO© tool.

Table 2. Prevalence by setting of advanced chronically ill, SQ+ and NECPAL+ patients.

	Population, n	Advanced chronically ill, n (%)	SQ+, n (%)	NECPAL+, n (%)
Primary care	51,595	731 (1.4)	557 (1.1)	524 (1.0)
General practitioner (n: 29)	1779[a]	24.9[b] (range: 16–37)	19.6[b]	17.8[b]
Nursing home	295	213 (72.2)	182 (61.7)	159 (53,9)
Social-health centre	92	87 (94.6)	64 (70.0)	64 (70.0)
District general hospital	161	69 (42.8)	67 (41.6)	60 (37.3)

SQ+: surprise question positive; NECPAL+: patients being SQ+, plus having at least one positive category from among the four categories of the NECPAL CCOMS-ICO© tool.
[a]Mean population served by each general practitioner.
[b]Mean number of recruited, SQ+ and NECPAL+ patients at home attended by each general practitioner.

Table 3. Population distribution of advanced chronically ill, SQ+ and NECPAL+ patients by age, gender and disease/condition.

	Advanced chronically ill (n = 1064)	SQ+ (n = 841)	NECPAL+ (n = 785)
Demographic characteristics			
Age (years), mean (SD)	81.3 (11.8)	81.7 (11.8)	81.4 (12.0)
Gender, n (%)			
Male	378 (35.5)	319 (37.9)	303 (38.6)
Female	686 (64.5)	522 (62.1)	482 (61.4)
Chronic disease or condition, n (%)			
Cancer	108 (10.2)	101 (12.0)	101 (12.9)
Lung	64 (6.0)	52 (6.2)	51 (6.5)
Heart	88 (8.3)	82 (9.8)	80 (10.2)
Neurological	79 (7.4)	54 (6.4)	48 (6.1)
Liver	16 (1.5)	15 (1.8)	15 (1.9)
Kidney	31 (2.9)	26 (3.1)	24 (3.1)
Dementia	204 (19.2)	186 (22.1)	184 (23.4)
Advanced frailty	407 (38.3)	285 (33.9)	246 (31.3)
Other chronic disease	43 (4.0)	25 (3.0)	22 (2.8)
Other	24 (2.3)	15 (1.8)	14 (1.8)

SQ+: surprise question positive; NECPAL+: patients being SQ+, plus having at least one positive category from among the four categories of the NECPAL CCOMS-ICO© tool; SD: standard deviation.

Discussion

Key results

For the first time in the world literature, a direct measurement of the prevalence of patients with advanced chronic conditions in need of PC in a whole geographic population has been determined. It has been done by health carers using the NECPAL CCOMS-ICO© tool.

NECPAL+ patients are mainly among the elderly population which is often living at home or in NH. Advanced

Table 4. Characteristics of NECPAL+ patients by setting of care and disease/condition.

Setting of care	Social-health centre	Nursing home	District general hospital	Home	*p* value
Age (years), mean (*SD*)	78.1 (11.8)	85.2(6.9)	76.8 (11.3)	80.3(12.9)	<0.001
Gender, *n* (%)					<0.001
Male	29 (52.7)	28 (18.2)	28 (56.0)	218 (41.5)	
Female	26 (47.3)	126 (81.8)	22 (44.0)	307 (58.5)	
Disease/condition, *n* (%)					<0.001
Cancer	15 (27.3)	2 (1.3)	13 (26.0)	71 (13.5)	
Organ failure	21 (38.2)	20 (13.0)	27 (54.0)	185 (35.2)	
Dementia	6 (10.9)	107 (69.5)	4 (8.0)	66 (12.6)	
Advanced frailty	13 (23.6)	25 (16.2)	6 (12.0)	203 (38.7)	
Disease/condition	Cancer	Organ failure	Dementia	Advanced frailty	*p* value
Age (years), mean (*SD*)	72.8 (14.0)	76.0 (14.1)	85.1 (6.5)	86.1 (7.1)	<0.001
Gender, *n* (%)					<0.001
Male	58 (57.4)	133 (52.6)	37 (20.2)	75 (30.4)	
Female	43 (42.6)	120 (47.4)	146(79.8)	172 (69.6)	

NECPAL+: patients being surprise question positive (SQ+), plus having at least one positive category from among the four categories of the NEC-PAL CCOMS-ICO© tool; SD: standard deviation.

frailty and dementia are the most common clinical conditions, followed by cancer and organ failure. There are higher proportions of women and non-cancer patients. These findings are consistent with our previous published estimates.[36] All of these individuals identified would benefit from a PC approach.

Strengths and limitations of the study

The study was carried out with 100% of participation from both health-care professionals and settings that needed to be involved, a common case identification methodology followed in all settings and a high level of commitment from all participants.

The study has some limitations. Due to non-probabilistic sampling applied, it is not possible to determine representativeness of study sample. However, the primary care centres were randomly selected, and represent 32.9% of the entire County's population. Availability of quantitative data in clinical charts may have affected description of patients' characteristics. The study results may have also been affected by ageing population and strong influence of geriatric care in the area, as well as by length of the study window. Finally, as this study was based on health professionals' assessment and routine data, patients' perspective was not included.

Previous experiences

To date, most surveys to identify these patients have been conducted in specific services such as primary,[25] hospital,[37,38] or NH;[39] identified patients with specific diseases;[27,40] or used mortality data.[13,41] There have been several attempts to identify needs in whole populations, either based on an estimation of the needs[10,42] or

the experiences of relatives of patients,[12] but none has identified patients directly on a population basis, considering any advanced condition, chronic or not, and using a tool as screening methodology.

Interpretation

The most relevant contribution of this study to the body of knowledge of PC consists in the innovative, systematic and prospective direct methodology of measuring – as opposed to estimating – the population-based prevalence of persons with advanced chronic conditions in need of PC.

Advanced frailty, as condition, and the combination of general clinical indicators of severity and progression are the most frequent causes of NECPAL+ identification and may result more appropriate than just individual diseases for elaborating a PC strategy.

Advanced frailty is a highly important indicator of impending mortality. Previously published predictor tools [22,23](mainly based on Fried criteria[43]) were designed to identify moderate frailty at an early stage. However, applying the NECPAL CCOMS-ICO© tool to detect advanced severe frailty, our results confirm that a different approach based on the accumulation of deficits would be more accurate.[44,45]

Four of six general clinical indicators of severity and progression correspond to deficits caused by advanced frailty, emphasising geriatric syndromes (with increasing evidence as an independent prognostic marker),[46] as well as use of resources and nutritional and functional markers, which are already considered in previous predictor tools.[22,23] These conditions are not usually registered in mortality registries, which usually record individual diseases. Moreover, the rate of decline of patients is considered as dynamic – in the last

Table 5. Characteristics of patients identified using NECPAL CCOMS-ICO© tool criteria.

	Missing		Advanced chronically ill		Missing		SQ+		Missing		NECPAL+	
	n	%	n	%	n	%	n	%	n	%	n	%
Category 1: 'Surprise question' SQ+	0		841	79.0	0		841	100.0	0		785	100.0
Category 2: Choice/demand or need	0		290	27.3	0		268	31.9	0		268	34.1
Patient's choice	4	0.38	51	4.8	4	0.48	44	5.2	4	0.51	44	5.6
Carer's choice	5	0.47	224	21.1	5	0.59	209	24.9	5	0.64	209	26.6
PC need identified by professionals	10	0.93	125	11.7	9	1.07	122	14.5	9	1.15	122	15.5
Category 3: General clinical indicators	4	0.38	909	85.4	4	0.48	741	88.1	4	0.51	741	94.4
Nutritional decline												
Clinical nutritional decline	11	1.03	255	24.0	10	1.19	238	28.3	10	1.27	238	30.3
Serum albumin < 2.5	525	49.34	26	2.4	394	46.85	25	3.0	355	45.2	25	3.2
Weight loss > 10%	620	58.27	46	4.3	463	55.05	43	5.1	440	56.05	43	5.5
Functional decline												
Clinical functional decline	6	0.56	391	36.7	6	0.71	346	41.1	6	0.76	346	44.1
Severe dependency (Barthel index < 20)	30	2.82	127	11.9	24	2.85	118	14.0	22	2.80	118	15.0
Loss ≥ 2 ADL	15	1.41	266	25.0	13	1.55	244	29.0	12	1.53	244	31.1
Geriatric syndromes												
Pressure sores Grade III–IV	9	0.85	36	3.4	8	0.95	34	4.0	8	1.02	34	4.3
Infections with systemic impact > 1	7	0.66	46	4.3	7	0.83	42	5.0	7	0.89	42	5.4
Confusional syndromes	4	0.38	140	13.2	4	0.48	123	14.6	4	0.51	123	15.7
Persistent dysphagia	5	0.47	88	8.3	5	0.59	82	9.8	5	0.64	82	10.4
Falls > 2	15	1.41	103	9.7	14	1.64	86	10.2	14	1.78	86	11.0
Severe emotional distress	41	3.85	199	18.7	37	4.4	166	19.7	31	3.95	166	21.1
Use of resources												
Urgent admissions ≥ 2	128	12.03	105	9.9	119	14.15	94	11.2	98	12.48	94	12.0
Increase in nursing care needs	35	3.29	181	17.0	31	3.69	147	17.5	29	3.69	147	18.7
Co-morbidity: Charlson index ≥ 2	133	12.5	636	59.8	123	14.63	521	62.0	101	12.87	521	66.4
Category 4: specific chronic disease indicators												
Cancer	11	9.32	82	69.5	11	9.91	81	73.0	10	9.09	81	73.6
Lung	12	16.67	50	69.4	12	20	41	68.3	11	18.97	41	70.7
Heart	12	12.12	69	69.7	12	12.9	65	69.9	11	12.22	65	72.2
Neurologic (vascular)	11	22.92	9	18.8	11	30.56	6	16.7	10	33.33	6	20.0
Neurologic (progressive)	11	22	33	66.0	11	28.95	25	65.8	10	27.78	25	69.4
Liver	0		14	51.9	0		13	50.0	0		13	52.0
Kidney	12	27.27	15	34.1	12	30	11	27.5	11	29.73	11	29.7
Dementia	12	5.58	186	86.5	12	6.12	172	87.8	10	5.18	172	89.1

SQ+: surprise question positive; NECPAL+: patients being SQ+, plus having at least one positive category from among the four categories of the NECPAL CCOMS-ICO© tool; PC: palliative care; ADL: activities of daily living.

6 months – instead of only static. This innovative approach, applied in a study sample with such high proportion of elderly people, would explain high prevalence found.

The combination of functional and nutritional decline, severe frailty, geriatric syndromes and dementia, multi-morbidity and the use of emergency and hospital

admissions create a 'cluster' of complex chronic patients representing 2%–5% of the total population.[47]

The distributions of the patients' characteristics (diagnoses, gender, age and clinical setting) could be related to their needs, the presence of primary carers and settings where the required resources are available. Older patients, women, with advanced frailty and dementia are often based in home and NH, while younger cancer and organ failure patients are more likely to be based in the DGH and in SHC, where oncology wards and the PC units are based.

Only one-quarter of identified cases made a request for PC or limitations to the use of major therapeutic interventions. When these requests occurred, they were mainly initiated by the patient's primary carer, which highlights the paternalistic nature of the Spanish cultural context.[48]

There was a moderate degree of agreement between doctors and nurses with different populations being identified as having SQ+ condition. Additionally, a minority of those patients were identified by them as needing PC. These findings emphasise the need to systematically screen for PC requirements in all target sub-populations and the importance of a multidisciplinary approach.

Our findings indicate a high concordance between the surprise question and the presence of at least one NECPAL CCOMS-ICO© tool additional parameter. This indicates that the detailed NECPAL CCOMS-ICO© tool indicators may be used subconsciously by clinicians to answer the surprise question.

Using the NECPAL CCOMS-ICO© tool had a considerable impact on the perceptions of the problem and on the clinical practice of the participating professionals, as has been observed in other settings.[49] Its consistent use across all clinical settings showed its feasibility, and that it can be applied in daily clinical practice using multidisciplinary clinical assessments, and the available basic tools.[33]

Generalisability

Our findings need to be confirmed by similar studies in different and equivalent demographic and care settings, both nationally and internationally. Generalisability will be enhanced by the use of Standardised Incidence Mortality Rates (SIMR) by age groups, if data from survival follow-up of identified patients in those equivalent and different demographic and care settings become available.

Perspective of the study findings and implications for policy

Early identification and determination of the prevalence of patients with PC needs is likely to be the cornerstone of future public health, community-oriented, population-based policies to improve PC for chronically ill patients.

This study confirms previous studies that identify the health-care burden created by chronic illness[6,50] and the

need to develop treatment protocols and systems to deal with frailty and multi-morbidity.[51]

There is a clear dissonance between the focus on cancer of most specialist PC services and deaths from other non-malignant causes. Our results indicate that a significant shift in thinking is required on how health systems worldwide manage the majority of patients at end of life.[52]

Early identified patients in need of a PC approach require a systematic assessment, review of treatment within a multidimensional therapeutic approach, advance care planning, case management and integrated care with other resources, since these would have an enormous impact on the quality of care[53] and efficiency of health-care systems.[54–56]

The role of primary care centres, NHs and specialist services in general hospitals and social-health PC services in the community needs to be re-evaluated, with clear responsibilities identified. Community services must be empowered to increase their capacity to respond to end-of-life needs.[57] Additionally, cooperation between primary care centres, specialist PC providers and gerontologists is recommended.[58]

National or regional chronic care programmes should incorporate the PC approach as one of the elements of a global policy. When implemented in a population-based comprehensive approach, such a policy would reach most of the patients with advanced chronic conditions who will need comprehensive end-of-life care.[47,59]

Implications for future research

Construct validation for the NECPAL CCOMS-ICO© tool (including predictive validation) is currently ongoing through different research projects: analysing survival status of identified patients, exploring a predictive model of death at 12 months – based on NECPAL CCOMS-ICO© tool indicators – and determining the SIMR as a way to validate the proposed identification strategy.

More research will be needed to describe the specific needs and demands of these patients, as well as the outcomes of individual and global early interventions arising from the improvement of the quality of community-based PC.[60]

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Declaration of conflicting interests

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