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Identifying chronic patients in need of palliative care in the general population:

development of the NECPAL tool and preliminary prevalence rates in Catalonia

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Abstract

Palliative care (PC) has focused on cancer patients within specialist services. However, around 75% of the population in middle and high-income countries die of one or more chronic advanced diseases. Early identification of such patients in need of PC becomes crucial.

In this feature article we describe the initial steps of the NECPAL (*Neces*idades *Pali*ativas; Palliative Needs) Programme. The focus is on: a) development of the NECPAL tool to identify patients in need of PC; b) preliminary results of the NECPAL prevalence study, which assessed prevalence of advanced chronically-ill patients within the population and all socio-health settings of Osona; and c) initial implementation of the NECPAL Programme in the Region.

As first measures of the Programme, we present the NECPAL tool. The main differences from the British reference tools on which it is based are highlighted. The preliminary results of the prevalence study show that 1.45% of the total population and 7.71% of the population aged over 65 are "surprise question" positive patients (SQ+), while 1.33% and 7.00%, respectively, are NECPAL positive patients(NECPAL+); surprise question positive and at least 1 additional positive parameter. More than 50% suffer from geriatric pluri-pathology conditions or dementia. The pilot phase of the Programme consists of developing sectorised policies to improve PC in 3 districts of Catalonia.

The first steps to design and implement a Programme to improve PC for chronic patients with a public health and population-based approach, are to identify these patients and to assess their prevalence in the health-care system.

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1. Introduction and background

a) *Conceptual transitions in palliative care* (Table 1)

Palliative care (PC) was initially developed in the British hospice movement in the
1960s, and spread into all services and countries, in the process of which different types
of services and models of organisation were developed. PC services have incorporated
conceptual transitions and identified challenges, the most relevant being to extend PC
beyond cancer. In the process there have been conceptual changes: from a disease-based
approach towards the introduction of geriatric conditions and syndromes; promotion of
early palliative interventions in the clinical evolution of the disease; identifying
complexity *versus* prognosis as criteria for specialist interventions. Palliative and
disease-specific treatments can be used concurrently, and are not incompatible or
antagonistic. Other care innovations include the use of the comprehensive model of care
and intervention together with advance care planning and case management as core
methodologies. From the epidemiological perspective, orientation has shifted from
cancer mortality to all chronic conditions, and from the concept of terminal disease to
"advanced chronic conditions with a limited life prognosis"[1] with several patterns, or
trajectories, of progression.[2] This approach supports the concept that PC measures
need to be applied in all settings of health-care systems (HCS). The population-based
approach to mortality and prevalence can be applied, preferably, in districts or
sectors[3] from the public health (PH) and political perspective.[4] Transitions outline
needs, demands and policies for improving PC in all settings. Together with instruments
to identify chronically-ill patients in need of PC, the policies decided-upon are key in
implementing actions.[5]

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b) Evolution of concepts of frailty, severity, progression, and prognostic tools in
patients with advanced chronic conditions

The criteria identifying a patient with an advanced disease combine levels of severity, progression, and advanced frailty. The concept of severity depends on the criteria for every specific disease, more than on the number of co-morbidities.[6] Also contributing to severity are general parameters such as: functional[7] or nutritional status,[8] inter-current infections, and the use of emergency health-care resources.[9] Some of the geriatric syndromes such as delirium,[10] dysphagia,[11] sores/ulcers [12] and falls [13] have shown significant correlations with mortality. The criteria of progression are those aspects necessary to assess the evolution of disease, the degree of reversibility, and the response to previous therapeutic measures. Frailty syndrome has been defined as a state of vulnerability and risk of health deterioration. It has been associated with mortality, especially if advanced and progressive. Frailty is frequently associated with chronic conditions and consists of deficit accumulation, with the probability of death exponentially related to the number of deficits and their progression over time. Clinically, frailty can be identified using the Multidimensional Geriatric Assessment (MGA), a specific tool with a strong relationship with survival time.[14]

c) Identifying PC needs in populations: mortality and prevalence

The assessment of PC needs in a population can be determined using a combination of methods.[15] Mortality from chronic conditions can be estimated listing the related causes of mortality. The results of this methodology show that, in high income countries, around 75% of the population will die due to chronic conditions, with a cancer-to-non-cancer ratio of 1:2. Our initial estimate of prevalence was based on the

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assumption of life-expectancy of the advanced-terminal condition of 3-6 months for

cancer, and 9-12 for non-cancer; the ratio of cancer-to-non-cancer being around 1:6-8.

d) Methods and tools to identify individual patients in need of PC

There are different experiences and associated prognostic tools to identify patients

needing PC measures.[16] The Prognostic Indicator Guidance at the Gold Standards

Framework (PIG/GSF) and the Scottish Prognostic Indicator Tool (SPICT)[17] were

designed and developed in the UK and have inspired similar tools elsewhere.[18]

The GSF/PIG and SPICT general tools combine the perception of the different health-

care professionals ("the surprise question") with the wishes and preferences of patients

with respect to limitations of curative therapies and insertion of palliative measures

("the choice question"). Clinical parameters (progressive, established and persistent

functional and nutritional decline), the presence of co-morbidities, and the use of

resources (especially emergencies) can be included as tools to identify advanced status

of specific conditions (cardiac, respiratory, or other). GSF implementation includes

identifying patients and instigating new processes of care, education and training in the

different settings, together with actions to improve quality, including setting-up

indicators to measure progress. Experiences of implementation of GSF, SPICT or

similar tools in settings such as primary care, hospitals and nursing homes have

demonstrated effectiveness in identifying patients in need, and improvements in care

quality in these settings.[19] The GSF-PIG / SPICT are especially useful because of

their simplicity, feasibility, and availability in all settings, and their usefulness in

identifying patients in need of PC, especially for non-cancer conditions.

e) The Catalonia WHO Demonstration Project for PC implementation (1990-2010)

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Twenty years ago, the WHO, in collaboration with the Catalan Department of Health began a WHO Demonstration Project (WHO DP) in PC, and achieved high coverage in Catalan health districts.[20] One of the aspects for improvement that was identified consisted of extending early PC provision for non-cancer patients into conventional services in all settings of the HCS. The NECPAL (from "***Nec**esidades **Pal**iativas"or "Palliative Needs" in Spanish) Programme is addressing this challenge as a PC Public Health Programme.[21,5]

f) Aims of this feature article

This feature article describes the initial actions of the NECPAL Programme in Catalonia. The main aims are to improve the quality of palliative care in the region. It focuses on the early identification and improved care of patients with advanced chronic conditions in the community. We summarise the preliminary results of this Programme in Catalonia. The initial focus is on constructing the NECPAL/WHOCC tool (based on the GSF/PIG and SPICT experiences, introducing other dimensions and adapted to our clinical and cultural context) to identify patients with these advanced chronic conditions (Appendix 1). We present the preliminary results of the prevalence of these patients in the general population in the County of Osona (north of Barcelona). The current state of the Programme focuses on developing a predictive model for 12-month risk of death for patients with chronic advanced diseases and life limiting prognosis while implementing different phases of the NECPAL Programme. Future communications will describe the end results of the prevalence study, the results of a prospective cohort study to explore the model's predictive capacity based on the NECPAL / WHOCC tool, and the results of the NECPAL Programme for improving PC in 3 pilot areas.

2. The NECPAL Programme

a) The NECPAL Programme Implementation

The NECPAL Programme is implemented by the Catalan Department of Health [22] within the context of the Programme for the Prevention and Care of Persons with Chronic Diseases [*Programa per a la prevenció i atenció de persones amb malalties cròniques*]. It proposes to identify patients suffering from an advanced chronic condition in all settings of the Catalan HCS, and activate an early palliative approach oriented towards improving the patients' quality-of-life. The general aim of this Programme is to improve quality of PC in all settings of the Catalan HCS, with focus in the community.

b) Palliative Care Needs Assessment

The initial steps of the NECPAL Programme have the main aim of assessing palliative care needs, via the framework of 2 research studies (PI10/01512 and 2010/PREVOsona), and consisting of 3 parts:

- Part I: Construction of a tool to identify patients with chronic advanced diseases needing palliative measures (the NECPAL/WHOCC tool)

- Part II: Determination of the prevalence of patients in need of palliative measures in the population of the County of Osona using the NECPAL tool, and to explore the prevalence in different settings of the HCS (primary care services, acute bed hospitals, social-health centres, and nursing homes)

- Part III: Exploration of the model's predictive capacity for 12-month risk of death based on the NECPAL tool, either globally or for selected chronic diseases and

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settings. The study is prospective in a cohort of patients with advanced chronic

diseases.

The NECPAL research studies have been designed by the WHOCC at the Catalan

Institute of Oncology (CIO) [*Institut Catala d'Oncologia; ICO*] in Barcelona. They are

developed jointly with primary-, geriatric-, and palliative-care health-care professionals

in Primary Care Services (PCS), at the Vic District General Hospital [*Consorci*

Hospitalari de Vic] and at the Santa Creu Hospital in the County of Osona. The projects

are sponsored by a start-up grant from the Health Investigation Foundation [*Fundacion*

Investigacion de Salud; FIS] of the Spanish Ministry of Health, and from the Catalan

Department of Health.

Both studies have been formally approved by the ethical research committees of

institutions involved in their execution (PI10/01512: PR200/10 and 2010/PREVOsona:

P10/65 and EO65)

c) Construction of the NECPAL/WHOCC tool

Selection of reference tools

Following a literature review, including a revision of a similar tool tested in a Spanish

acute bed hospital,[23] the PIG/GSF and SPICT tools were selected for their relevance,

feasibility and experience as sources from which to derive the main criteria for the

NECPAL tool.

Translation

A translation into Spanish of the relevant items of PIG/GSF and SPICT was performed

using a dual panel approach without back-translation. Cultural and clinical adaptation,

cultural understanding, and appropriateness of questions in the Spanish language as well

as the addition of new questions relevant for Spanish health-care professionals were

taken into account. The process involved 3 successive rounds of adaptation (from initial

translation into Spanish to the inclusion of cultural and clinical modifications).

Assessment of content validity

The proposed tool was evaluated by a multi-disciplinary expert panel and included 18

semi-structured interviews (Appendix 2). Opinions were solicited from the experts in

terms of overall, as well as specific, appropriateness of the tool in identifying patients in

need, as well as the comprehensiveness and feasibility within the individual contexts.

Additionally, opinions were collated regarding the tool's ability to identify terminally-ill

status within the individual clinical specialties.

Pre-test

The process of pre-testing the NECPAL tool for comprehension and face validity

included primary care settings in which 17 interviews were performed. Following 5

version of the tools being tested (from pre-test to final version), this phase concluded

with the definitive NECPAL tool being put-together ready for use.[24]

T*he NECPAL/WHOCC tool*

The NECPAL/WHOCC tool translated into English is shown in Table 2. Compared

with the GSF and SPICT, the main differences are:

- The "surprise question" is maintained for the next 12 months

- The "choice question" has the concept of "demand" introduced, and has been

 adapted to our Latin-Mediterranean cultural context in which the family members

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(or carers) are more involved in decision-making regarding the patient. We

introduce the concept of "need" for limiting therapies, or the introduction of PC, as

perceived/indicated by the health-care professional.

- The clinical parameters had the psychosocial area (severe persistent emotional

  distress or adjustment disorders) introduced as well as the commonest geriatric

  syndromes (severe frailty, falls, persistent pressure sores, repeated infections,

  delirium).

- The combinations of the concepts of severity and progression not linked to an acute

  process were introduced

- Frailty was introduced as a general and transversal indicator

- The proposed parameter of resource use refers to emergency department access in

  the previous 12 months.

- There are proposals to identify advanced illness status in several specific conditions

Additionally, 2 further formats have been edited and adapted for different purposes [25]

i.e. 1) leaflet format: designed to be easily available in clinical practice; and 2) research

version format: oriented towards studies promoting the spread of epidemiological and

clinical data collection, and quality improvement in services.

The NECPAL/WHOCC document

A guide (termed the NECPAL DOC) has been edited to consist of the

NECPAL/WHOCC TOOL, with an introduction and two additional sections: 1) *6 basic*

recommendations for care provision for identified patients (oriented towards practical

actions for patient care); and 2) *6 basic recommendations to improve the quality of PC*

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in the HCS (oriented towards implementing actions for improving the quality of PC in any health care service).

d) Determination of prevalence

The study was implemented in the County of Osona; a region of 1,260 sq km located to the north of the Province of Barcelona. The mixed urban-rural population consists of 147,138 inhabitants; 21.4% >65 years of age and an overall mortality of 8.81‰. The County of Osona has a complete range of health- and social-care resources including: 11 PCS, a District General Hospital (DGH) of 160, beds, 2 Social-Health Centres (SHC) including rehabilitation, PC, long-term care and dementia-care facilities, and 22 nursing homes. It also has a comprehensive system for geriatric, dementia, palliative and chronic care. All facilities within the HCS are linked by a common computerized information system, the Osona Integrated Health System (OIHS) [*Sistema Integral de Salut de Osona; SISO*].

Sample and recruitment of services and patients

A representative random sample consisting of: 3 PCS stratified as urban, rural, and rural-urban; the inpatient units of the Acute Bed Hospital; one of the two Social-Health Centres; and the Nursing Homes registered at the Primary Care Services were selected for the conduct of the prevalence study. All care centres selected (9 of 9 contacted) accepted the invitation to participate in the prevalence study.

Methodologies for recruitment of patients were similar in all selected settings (Figure 1). Patient recruitment was based on interviews with health-care professionals (doctors and nurses) using all conventional clinical information available. The process

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encouraged enhancing / promoting sensitivity in recruiting all patients with chronic

conditions and highlighting the "advanced" (or "severely affected") in every disease or

condition (1st level). To determine the prevalence of patients with advanced chronic

conditions in need of PC measures, we defined the "negative" response (i.e. "I would

not be surprised…") to the Surprise Question (or "SQ + patients") as the 2nd level and

having at least 1 more positive parameter (or "NECPAL + patients") as the 3rd level.

Patients are followed-up for survival every 3 months for a period of 1 year. Overall

mortality in the studied area is recorded and compared whether the individual had been

identified, or not, in each level.

Determination of population-based / community prevalence

Prevalence was calculated from all patients recruited by the selected PCS using the SQ

+ at least 1 additional parameter. To this was added the number of patients recruited

over the same period at the social-health centres, acute-bed hospital, and nursing homes

registered in the PCS. Once identified, the prevalence was calculated with the formula:

number of patients identified ÷ the total population ÷ the adult population over 16 years

of age.

The most relevant preliminary results are shown in the Tables 3, 4, and 5. The complete

results are currently undergoing detailed analysis.

Qualitative analysis of the impact of the study conducted in PCS

In the 3 PCS included in the prevalence study, 2 focus groups of 8 health-care

professionals were organised. The composition was multi-disciplinary, with a conductor

and an observer. The dimensions discussed included: process of selecting patients;

feasibility of the instrument; impact of the SQ; use of subjective and objective

parameters. These sessions were followed by discussions on types of interventions for

the care of the patients identified, clinical priorities, decision-making, training needs,

and demands. All discussions were video taped and reviewed during post-discussion

analysis.

There was consensus regarding the positive influence of the NECPAL tool application

and its implementation in the quality of care. The most relevant aspects were: "sharp

awareness" of the high prevalence of these patients in primary care practices; practical

feasibility; value of the surprise question as a qualitative approach which modifies

personal and professional attitudes; value of the interdisciplinary approach; need and

demand for education and training; need for changes in organisation of PC services and

their relationship with specialist services.

e) Development of a predictive model for 12-month risk-of-death study

Patients from Acute-bed Hospitals, SHC, NH and PCS with the most common chronic

diagnoses are currently being recruited into an observational, analytic, prospective

cohort study to develop a predictive model for 12-month risk–of-death, based on

identification of patients using the NECPAL tool. The model's overall predictive

capacity will be studied, as well as segregated by disease and setting. The data will be

presented in future communications.

f) The NECPAL Programme at the Department of Health (DoH)

The initial phase of insertion of the NECPAL project into the Programme for Chronic

Care at the DoH consisted of defining the Programme as one of the issues to be

implemented within the context of the Chronic Care Programme, and the selection of 3

demonstration areas: County of Osona (mixed urban/rural area); Girona (urban area);

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Barcelona South (metropolitan area). The current process of implementation consists in developing an action plan for every area, including systematic actions (context & quantitative analysis, managerial workshop, clinical workshop, prevalence survey, implementation (clinical and organisational measures) and evaluation (establishing monitoring indicators).

3. Discussion

a) *Construction and cultural validation of the NECPAL tool*

The NECPAL tool has incorporated some issues to be adapted to our cultural context such as the inclusion of the family members (as well as team members) in the "choice question", in a paternalistic context where the patients are less autonomous and families take responsibility for information and decision-making.[26] The inclusion of the combination of severe and progressive frailty is due to its high prevalence (not necessarily linked to individual diseases) and the severe psychological distress (or difficulties in adjustment to the clinical condition) based on the assumption that these dimensions are also indicators of the need of PC interventions.

Regarding the assessment of frailty, there are two significant differences between the NECPAL tool and PIG /GSF and SPICT:

a) The NECPAL tool presents frailty not as a separate clinical entity, but as a general and transversal indicator of mortality, beyond the patient's illness trajectory. This fact is related to the reality of patients at the end of life, where the most prevalent chronic situation is multimorbidity [27]

b) PIG/GSF and SPICT measure frailty mainly based on Fried criteria [28] (weakness, slow walking speed, low physical activity, weight loss, reduced weight loss, self reported exhaustion), basically oriented for the detection of initial/moderate frailty.

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For the detection of advanced frailty, which is the common path towards the end of life for many patients (especially those over 75 years), the most rational approach is based on deficits accumulation.[14] Four out of the six general indicators correspond to deficits caused by advanced frailty, emphasizing geriatric syndromes (with increasing evidence as an independent prognostic marker),[29] as well as use of resources and nutritional and functional markers, as already considered in PIG/GSF and SPICT.

c) In the NECPAL tool, severity and progression criteria have been proposed as the backbone of measurement of proposed variables -including those related to the disease and, especially, when assessing general indicators, which are increasingly seen as the most reliable markers of advanced situation, especially in "geriatric profile" population,[30] with a dynamic perspective, including the temporal dimension.

These changes could explain the increased length of the NECPAL tool as compared with the reference ones. The preliminary results of the prevalence study emphasize the importance of including the geriatric syndromes in the NECPAL tool and actively searching for these conditions in the identification process.

b) Preliminary results of the population prevalence study

The sample of services and patients is representative of the county. The most striking result is the high figure obtained for overall prevalence (1.45%), possibly due to the higher proportion of elderly (21.4 *vs.* 17%) in the area, and the inclusion of advanced geriatric pluri-pathology and frail patients in the recruitment. This is reflected in a prevalence of dementia >50% of SQ+ patients, and the mean age of SQ+ of >81 years. The proportion of cancer patients is consistent with our previous estimations. The

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prevalence by settings (PCC, Hospitals, SHC, and NH) could be a local feature, and

needs to be evaluated in other contexts. Most of the patients live within the community

and nursing homes, and are followed-up by the PCS, with few interventions by

specialist services. This feature is crucial for planning and developing policies to

improve PC with a PH approach. The complete results of the prevalence study and the

preliminary results of the survival study are currently being analysed.

c) Early identification in the community

The pattern of PC of these patients needs to change towards an earlier, gradual and

flexible approach in which palliative care and all other measures must be combined, and

initiated in community services months before death (Fig. 2).

d) Piloting the NECPAL tool in PCS

The NECPAL tool has been considered feasible, practical and useful by PC doctors and

nurses in identifying patients with advanced conditions in need of PC measures.

The qualitative study showed that the use of the NECPAL tool has a considerable

impact on the perceptions, and eventually in clinical practice, of primary-care

professionals, as has been observed in other experiences.[31] The identification of

patients, and their high prevalence in the community, produces a "sharp awareness" in

primary-care professionals, and leads to identifying an unexpected level of needs even

in the absence of demands (the "surprised team"). Of considerable interest is that one of

the most relevant parameters in identifying patients is the "surprise question" which,

when contemplated by doctors and nurses, involves them more personally than other

parameters or tools.

Another relevant feature is the identification of the need and demand for training of the

health-care professionals in the community in order to manage these patients from an

early stage. The organisation and quality of the PCS need to change to adjust to the

prevalence. The role of specialist services acting in the community also needs to

change, especially when patients are identified earlier and, presumably, are less

clinically complex.

4. **Conclusions, recommendations and further progress**

The first steps of a Programme to improve palliative care in Catalonia are described.

Included are the construction of the NECPAL Tool, the preliminary results of the

prevalence study, and the impact on primary-care professionals.

The NECPAL tool is adapted to our (Mediterranean) cultural settings. It is feasible, and

is accepted by primary-care professionals. It can identify quite easily those patients in

need of PC measures from among those suffering from advanced chronic conditions

living in the community. Identification is at an early stage and the estimated survival

time is around 12-14 months. It is recommendable as a screening tool to identify these

patients not only in primary care but also in all the conventional resources in the HCS.

The process of identifying patients has a considerable impact on PC professionals and

service providers. It increases awareness of prevalence and needs of the patients. Also

highlighted is the need for specific training of the health-care personnel and for adapting

the organisation of PCS and other health and social care settings to the needs of the

population.

In our ongoing research studies, we are determining the prevalence of patients with PC

needs in specific settings (Hospitals, NH, SHC) in other districts, we are seeking to

identify the most relevant clinical features -including the description of those needs-, as

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well as the predictive capacity of the parameters included in the tool, so as to select the

most relevant and reliable, and conducting the longitudinal study on the causes of death

of the identified patients.

There is enough evidence already to recommend implementation of the NECPAL

Programme in Catalonia in all services. The objective is to combine the NECPAL tool

with measures that respond to individual needs of these patients which, together with

general measures, would improve the quality of PC in all settings. The sectorised

approach would enhance a population-based PH vision, adapted to local needs.

Knowledge of the prevalence of patients with advanced chronic diseases with limited

prognosis in need for palliative measures in populations and settings of the health and

social organisations is fundamental for planning and implementing PC programmes, and

measures to achieve coverage for all patients.

Limitations of this feature article

This article describes the initial actions of a Programme, including the construction and

adaptation of a tool to identify patients with chronic advanced diseases in need of PC in

a County within Catalonia. Also described are the preliminary results of the prevalence

rates in a population-based study. These actions are the first steps (needs assessment) of

the NECPAL Programme.

Although the tool is not currently undergoing a formal process of validation, there is

considerable agreement among the relevant experts regarding its use. The results of the

prevalence study and the qualitative survey of the focus groups reflect this agreement.

The preliminary results of prevalence are derived from one specific district in Catalonia,

and further studies are ongoing in other settings to evaluate the reproducibility of our

findings.

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Acknowledgements

Tables

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Table 3. Preliminary results of the NECPAL prevalence study
Table 4. Some characteristics of "surprise question" (SQ+) patients
Table 5: Distribution of SQ+ patients

Figures

Figure 1. Recruitment of patients (Doctor & Nurse in every setting)
Figure 2. Earlier detection, longer time of intervention/survival and place & type of service of patients with PC needs 1985-2011

Appendices

Appendix 1. The NECPAL TOOL (Spanish general version which does not include items for specific diseases)
Appendix 2. Members of the Expert Panel

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Competing Interests

Authors of this manuscript have no competing interests.

Data sharing statement

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No additional data

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TABLES,

Table 1. Conceptual transitions in PC in the 21st Century

Change FROM	Change TO
Terminal disease	Advanced progressive chronic disease
Prognosis of weeks or months	Limited life prognosis
Cancer	All chronic progressive conditions
Progressive course	Progressive course with frequent crises of needs and demands
Disease	Condition (multi-pathology, frailty, geriatric syndromes, dependency)
Mortality	Prevalence
Dichotomy curative - palliative	Synchronic, shared, combined care
Specific *OR* palliative treatment	Specific *AND* palliative treatment as needed
Prognosis as criteria for intervention of specialist services	Complexity as criteria
Rigid one-directional intervention	Flexible shared intervention
Passive role of patients	Advance care planning
Palliative care services	Palliative care approach everywhere
Specialist services	Actions in all settings of health- and social-care
Institutional approach	Community approach
Fragmented care	Integrated care

2

Table 2. The NECPAL/WHOCC Tool (differences from the PIG and SPICT tools

highlighted in red)

Surprise question	Would you be surprised if this patient dies within 1 year?	
Need, demand and choice	Any request to limit the treatments or palliative care from patient, family, or team members?	
General clinical indicators (severe, progressive, sustained)	Nutritional decline	Weight / albumin
	Functional decline	KPS or Barthel
	Geriatric syndromes (advanced frailty)	Pressure ulcers Infections Disphagia Delirium Falls
	Severe psychological adjustment difficulties	Numerical Verbal Scale / HADS test
	Co-morbidity	≥2 chronic diseases
	Use of resources	≥2 urgent admissions in 12 months Or increase in need / demand of care
Specific indicators	Cancer, COPD, Heart, Hepatic or Renal Failure, Neurological, Stroke, Dementia	

3

Table 3. Preliminary results of the NECPAL prevalence study

	SQ+ & NECPAL + / over 1,064 recruited	% of total population	% of Population > 65 years of age
Total Chronic Patients Recruited (Level 1)	1,064	2.06%	10.91%
Surprise Question (SQ-) = + (Level 2)	750 (70.5%)	1.45%	7.71%
NECPAL + (SQ + 1 more item) (Level 3)	684 (64.3%)	1.33%	7.00%

4

Table 4. Some characteristics of "surprise question" (SQ+) patients
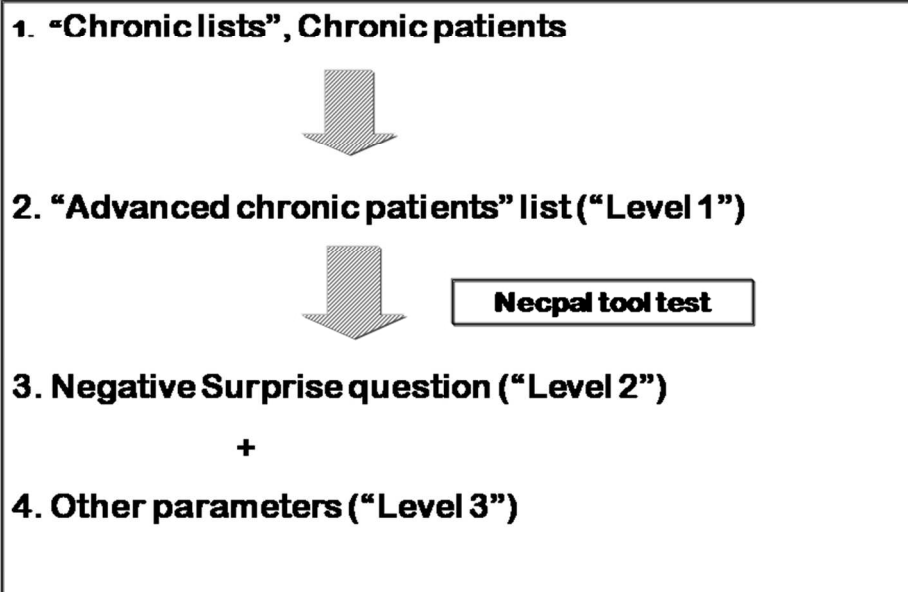
Age of recruited SQ+ by gender

Age	N	Mean (SD)
Male	289	76.89 (13.57)
Female	461	84.77 (9.77)
Total	750	81.73 (12.01)

Distribution of recruited SQ+ by setting

Setting	N (%)
Home	485 (64.67)
Nursing home	166 (22.13)
Social-health Centre	50 (6.67)
Acute-bed Hospital	49 (6.53)
TOTAL	750 (100)

5

Table 5: Distribution of SQ+ patients by main disease or condition

Disease or Condition	N	*%*
Cancer	95	12.67
Chronic respiratory disease	48	6.4
Chronic cardiac disease	79	10.53
Chronic neurological disease	42	5.6
Chronic hepatic disease	15	2
Chronic renal disease	22	2.93
Dementia	176	23.47
Advanced frailty	238	31.73
Other chronic diseases/conditions	24	3.20
TOTAL	750	100

Recruitment of Patients (Doctor & Nurse in every setting)
81x60mm (300 x 300 DPI)

UK hospices 80*: 21 days

HCST/HST : 80 days

ICO outputs: 8 months

+ NECPAL Tool (community, hospital services, nursing homes, social-health centres): 12-14 months
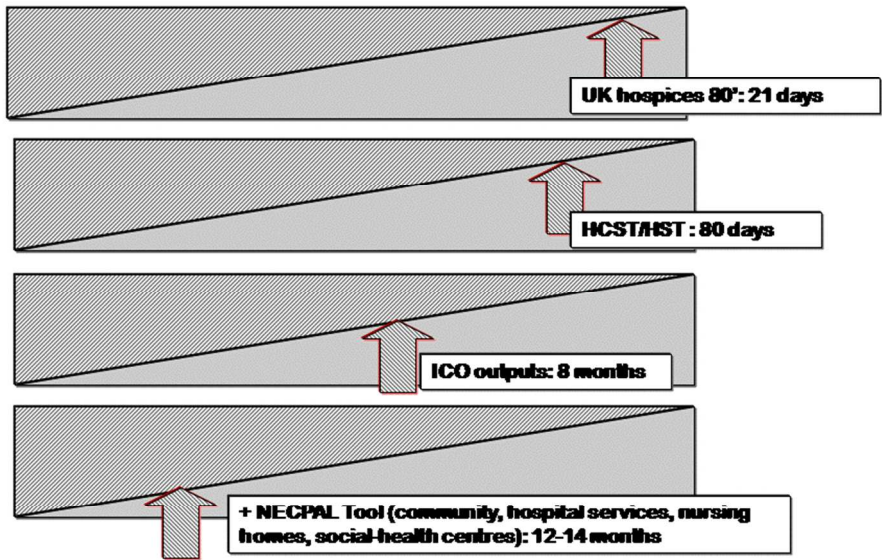
HCST: Home Care Support Team; HST: Hospital Support Team; ICO Output: Palliative Care Outpatient Clinic at the Catalan Institute of Oncology; + NECPAL Tool: patients identified by the NECPAL tool

Earlier Detection, longer time of intervention/survival and place and type of service of patients with PC needs 1985-2011
81x60mm (300 x 300 DPI)

Appendix 1. The NECPAL TOOL (Spanish general version which does not include

items for specific diseases)

NECPAL TOOL - WHOCC©

TOOL FOR THE IDENTIFICATION OF PERSONS IN ADVANCED-TERMINAL DISEASE STATE AND REQUIRING

PALLIATIVE CARE IN HEALTH AND SOCIAL SERVICES

What purpose does the NECPAL - WHOCC© tool serve?

- The strategy of identification of patients requiring PC measure, especially in general services (primary care and general hospital facilities etc),

- The intention of the NECPAL - CCOMS© tool is to identify patients who require whatever type of palliative measures

- Once the patient is identified, PC needs to be initiated consisting of the application of recommendation as explained in the "*6 steps for Palliative Care*" (see later)

- The identification of the status **does not contraindicate nor limit treatment measures specific for the disease** if they are indicated, or can improve the status, or the quality of life of the patients

- The palliative measures can be implemented by any team within the health service

What purpose does the NECPAL - WHOCC© tool NOT fulfil?

- To determine prognosis and survival

- To contraindicate, necessarily, the adoption of measures of control of the disease nor the treatment of inter-current processes

- To define the criteria of intervention of specific palliative care teams, intervention that in all cases, would be determined by the complexity of the case and the intervention proposed

- To reject curative therapeutic measures that can improve the quality of life

To whom should the NECPAL - WHOCC© tool be administered?

To persons with advanced chronic progressive disease with related associated diagnoses and status:

- Patient with **cancer** especially affected by the disease

- Patients with **chronic lung disease** especially affected by the disease

- Patient with **chronic heart disease** especially affected by the disease

- Patient with **chronic neurological disorder** (including stroke, Parkinson's Disease, motor-neurone disease) especially affected by the disease

- Patient with **chronic liver disease** especially affected by the disease

- Patient with **chronic renal disease** especially affected by the disease

- Patient with **dementia** especially affected by the disease

- **Geriatric** patient who, despite not suffering any of the above diseases, is in a **particularly advanced fragile state**

- Patient who, despite not being geriatric nor suffering any of the above diseases, suffers from **any other chronic disease that is particularly severe and advanced**

- Patient who, although not included in the above groups, needs to be **admitted to hospital or attended-to at home with greater intensity that expected**

What is considered a positive identification?

Any patient with:

- **Surprise question** (question 1) with a **NEGATIVE** answer, and

- At least **one other question** (2, 3 or 4)with **POSITIVE** answer according to the established criteria

What are the *6 Steps for Palliative Care provision*?

The recommendations for PC provision for patients identified are summarised as::

1. Identify Multidimensional needs

2. Apply the most appropriate Model of Care

3. Develop a Multidimensional and Systematic Therapeutic Plan (Square of Care)

4. Identify values and preferences of the patient: Clinical Ethics and Advanced Care Planning

5. Involve the family and the principal carer

6. Case management, follow-up, continuous and emergency care, coordination and integrated actions and services

NECPAL-WHOCC© TOOL

TOOL FOR THE IDENTIFICATION OF PERSONS IN ADVANCED-TERMINAL DISEASE

STATUS AND THEIR NEEDS FOR PALLIATIVE CARE IN HEALTH AND SOCIAL

SERVICES

1. THE "SURPRISE" QUESTION – an intuitive question that integrates co-morbidities, social aspects and other factors	
Would it surprise you if the patient dies within the next 12 months?	☐ No ☐ Yes

2. OPTION / DEMAND OR NEED – check if either of the following 2 questions are answered in the affirmative	
Option / Demand: has the patient with advanced disease, or the principal carer, **solicited** explicitly or implicitly the administration of palliative care or best supportive care, proposed any limitation on therapeutic effort, or rejected specific treatment, or treatment with curative intent?	☐ Yes ☐ No
Need: has the patient actually requested palliative measures, or palliative treatment?	☐ Yes ☐ No

3. GENERAL CLINICAL INDICATORS OR SEVERITY AND PROGRESSION: – check for the presence of any of the following criteria of severity and extreme fragility	
Nutritional markers, any of the following in the **previous 6 months:** ☐ Severity: serum albumin <2.5 g/dL, not related to acute decompensation ☐ Progression: weight loss >10% ☐ Clinical impression of nutritional deterioration or ponderal status, intense/severe, progressive, irreversible and not related with inter-current processes	☐ Yes ☐ No

Functional markers, any of the following in the **previous 6 months** ☐ Severity: severe, established functional dependency (Barthel <25, ECOG >2, Karnofsky <50%) ☐ Progression: loss or ≤ 2 on the BDLA (basic daily life activities) despite appropriate therapeutic intervention ☐ Clinical impression of sustained/intense/ severe/ progressive/irreversible deterioration not related to inter-current processes	☐ Yes ☐ No
Other markers of severity and extreme fragility, at least 2 of the following in the **previous 6 months:** ☐ Persistent pressure sores (stages III – IV) ☐ Recurrent systemic infections (>1) ☐ Acute confusional syndrome ☐ Persistent dysphagia ☐ Falls (>2)	☐ Yes ☐ No
Presence of **emotional distress** with psychological symptoms that are sustained, intense/severe, progressive and not related with acute inter-current processes	☐ Yes ☐ No
Additional factors requiring resource use, any of the following: ☐ 2 or more emergency admissions (not scheduled) to Hospital of Social Health Centres for chronic illness in the previous 1 year ☐ Need for complex care /continuous care whether in an institution or at home	☐ Yes ☐ No
Co-morbidity: ≥2 concomitant pathologies	☐ Yes ☐ No

Appendix 2: Members of the Expert Panel

Professions	Doctors, nurses, social workers, psychologists
Settings	Acute-bed Hospital, Cancer Centre, Social-health Centre, Primary Care
Specialty	Primary Care, Oncology, Geriatrics, Internal Medicine, Neurology, Pneumology, Nephrology, Palliative Care
Names	Albert Tuca, Josep Porta, Cristina Garzón, Núria Codorniu, Anna Albó, Maica Galán, Isabel Brao, Eduard Batiste Alentorn, Joan Casadevall, Josep Sadurní, Joan Saló, Eugènia Castellote, Josep Mª Aragonés, Francesc Formiga, Matilde Barneto, Lorena Bajo, Juan Carlos Contel, Jorge Maté