RECOMMENDATIONS FOR THE COMPREHENSIVE AND INTEGRATED CARE OF PERSONS WITH ADVANCED CHRONIC CONDITIONS AND LIFE-LIMITED PROGNOSIS IN HEALTH AND SOCIAL SERVICES:

NECPAL CCOMS-ICO© 3.1 (2017)

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CÀTEDRA DE CURES PAL·LIATIVES

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WHO COLLABORATING CENTRE PUBLIC HEALTH PALLIATIVE CARE PROGRAMMES

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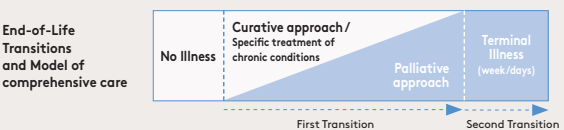
INTRODUCTION

Background

70% of deaths in high-income countries are caused by progressive advanced chronic conditions. Around 1-1.5% of persons suffer from advanced chronic illnesses and have life-limiting prognosis. These patients are present in all health and social services in variable proportions. The presence of advanced and progressive illnesses which determine prognosis limitations and the need of a gradual palliative care approach define the concept of first transition.



The WHO recommends promoting early identification of people with chronic conditions in all health services for timely and comprehensive palliative care provision. Nowadays, there are simple and validated clinical tools to identify such patients effectively. In our context, the NECPAL CCOMS-ICO© tool has been developed and validated to identify these patients with palliative care needs and life-limited prognosis. It has been revised by the Catalan Committee of Bioethics (Spain), among other care committees. Based on the recent experience acquired, and international cooperation, we have introduced some elements for improvement.

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- **http://mon.uvic.cat/catedra-atencion-cuidados-paliativos/**
- **http://ico.gencat.cat/ca/professionals/serveis_i_programes/observatori_qualy/eines_de_suport/eines/instrument_i_programa/**

Use and Advantages

Screening and determination of prevalence in services
Identification of persons in need of a palliative approach
Checklist of needs
Prognostic issues to be determined

- The NECPAL's main objective is to early identify persons with palliative care needs and life-limiting prognosis (in the so-called 1rst transition) in health and social services to actively improve the quality of their care, by gradually installing a palliative approach which responds to their needs. This comprehensive and person-centred approach, focused on improving the quality of life of patients, combines a multidimensional assessment with Advance Care Planning and explores patients' values and preferences. It also includes the revision of treatments and the development of an integrated care model in all settings by actively involving patients (and families) and healthcare professionals. This approach also promotes patients' right to receive a comprehensive and integrated care.
- In services with high prevalence of patients with complex and advanced chronic conditions, a screening should be performed in order to determine the prevalence of target patients, and promote the adoption of systematic policies of improving the quality of palliative care (training, changes of the organization).
- The dimensions of the NECPAL tool allow a checklist multidimensional approach
- Although recent data allow the identification of the risk of mortality at mid-term basis, this utility needs to be used cautiously, especially in the care of individual patients.

Considerations to bear in mind

- The surprise question and the other parameters must act as a "trigger" of a "palliative approach", to start a "reflexive process".
- The gradual insertion of this "palliative approach" must be compatible, inclusive, and synchronic with treatments focused on symptoms control, and concurrent curative processes, avoiding dichotomy.
- It does not determine the need of a palliative care specialist service intervention, which must be decided according to complexity and based on flexible and adapted intervention models
- Although recent data show corelation with mortality risk, the tool does not seek to determine prognosis as its main objective, and this applicability must be used with caution, as a "prognostic approach" or "vision".

Ethical aspects of timely identification

- Timely identification aims at actively improving the quality of care through inserting a palliative approach, which has shown benefits for patients
- It promotes equity, needs coverage, universal access, and the exercise of patients' right to quality care.
- Active measures to reduce possible risks of its misuse, such as stigmatization, losing curative opportunities, or the negative impact in patients need to be established. Such risks can be substantially reduced through the active participation of patients, the training of all professionals in palliative techniques, the open access to relevant clinical information, the adoption of quality improvement measures, and the active participation of the ethical committees in its implementation.

HOW TO USE THE NECPAL CCOMS-ICO© TOOL VERSION 3.1 2017

Procedure (first steps)to identify persons in services: to produce a "list of especially affected persons with advanced complex chronic illnesses":

1. To generate a list of patients with complex chronic conditions according to existing clinical information (age, diagnostics, severity, use of resources, etc.) and knowledge of patients.
2. Target patients: "Chronic with special impact of their conditions": patients with severe impact, progression, polypharmacy, multi-morbidity, or high demand.
3. Start NECPAL: SQ + other parameters

General recommendations:

- Use clinical parameters based on the experience and the knowledge of patients, complemented with validated instruments (additional or complementary explorations are not needed).
- Professionals: doctors and nurses knowing the patient's evolution. An interdisciplinary approach (participation of physician, nurse, psychologist or social worker among other professionals) is recommended.
- Setting: any service of the health system (not recommendable in emergency wards, in wards before 3 days of admission where the professionals do not know the patient).

NECPAL CCOMS-ICO© TOOL VERSION 3.1 2017

Surprise question (to/among professionals):

Would you be surprised if this patient dies within the next

"Demand" or "Need"	- Demand: Have the patient, the fa palliative care or limitation of ther
	- Need: identified by healthcare prof
General Clinical Indicators: 6 months - Last 6 months - Not related to recent/ reversible intercurrent process	- Nutritional Decline
	- Functional Decline
	- Cognitive Decline
Severe Dependence	- Karnofsky <50 o Barthel <20
Geriatric Syndromes	- Falls - Pressure Ulc - Dysphagia - Delirium - Recurrent infections
Persistent symptoms	Pain, weakness, anorexia, digestive..
Psychosocial aspects	Distress and/or Severe adaptive disc
	Severe Social Vulnerability
Multi-morbidity	>2 chronic diseases (from the list of
Use of resources	Evaluate Demand or intensity of interventions
Specific indicators of illness severity/progression	Cancer, COPD, CHD, Liver, Renal, CV Dementia, Neurodegenerative disea AIDS, other advanced illnesses

t year?

YES, I would be surprised → **NOT NECPAL**

NO, I would not be surprised

		NECPAL Parameters
mily or the team requested in implicit or explicit manner, apeutic effort?		1
fessionals from the team		2
	• Weight loss > 10%	3
	• Karnofsky or Barthel score > 30% • Loss >2 ADLs	4
	• Loss > minimental or > 3 Pfeiffer	5
	• Clinical data anamnesis	6
ers	• Clinical data anamnesis ≥ 2 geriatric syndromes (recurrent or persistent)	7
.	• Symptom Checklist (ESAS) ≥ 2 persistent or refractary symptoms	8
rder	• Detection of Emotional Distress Scale (DME) > 9	9
	• Social and family assessment	10
specific indicators)		11
	• > 2 urgent or not planned admittances in last 6 months • Increase Demand / intensity of interventions (homecare, nurse interventions, etc)	12
/A, ses,	• To be developed as annexes	13

If there is at least 1 NECPAL Parameter: **NECPAL +**

NECPAL + = **PS+** "I would not be surprised" + At least 1 parameter associated

Codification and Registry:

They help to visualize the condition of "Advanced chronic patient" in the clinical available and accessible information

- Codification:

A specific code, as "Advanced chronic patient", should be used, as opposed to the common ICD9 V66.7 (terminal patient) or ICD10 Z51.5 (patient in palliative care service).

- Registry

Clinical Charts:

After the surprise question, the different parameters should be explored, and add + according to the positives found

Shared Clinical Chart:

Always match codification and registry of additional relevant clinical information that describes the situation and recommendations for care in specific previsible scenarios and other services (In Catalonia, PIIC)

ANNEX 1

SPECIFIC NECPAL CRITERIA SEVERITY / PROGRESSION / AVANCED DISEASE [1] [2] [3] [4]

Cancer	• **Metastatic** or advanced locoregional • **Cancer** in progression (solid tumours) • **Persistent**, **uncontrolled or refractory symptoms** despite optimising specific treatment
Chronic Lung disease	• Dyspnea of breath at rest or minimal exertion • Confined to home with severe limitation • Spirometric Criteria of severe **obstruction** (VEMS <30%) o criteria severe restrictive (CV <40% / DLCO <40%) • **Basal gasometric criteria** of chronic oxigen therapy at home • Need of continous **corticotherapy** • Associated **symptomatic heart failure**
Chronic Heart disease	• Dyspnea of breath at rest or minimal exertion • **Heart failure** NYHA stage III or IV, **non-surgical severe valvular disease** or non-surgical **advanced coronary disease** • **Basal ecocardiography**: FE <30% or HTPA severe (PAPs > 60) • Associated **renal failure** (FG <30 l/min) • Association with **renal failure** and **persistent hyponatraemia**
Dementia	• **GDS ≥ 6c** • Progression of functional, nutritional, and/or cognitive declines
Frailty	• **Frailty index ≥ 0.5** (Rockwood K et al, 2005) • **Comprehensive Geriatric Assessment** suggesting advanced frailty (Stuck A et al, 2011)
Chronic Vascular Neurological Disease (stroke)	• **During acute and sub-acute phase** (< 3 months after stroke): persistent vegetative or minimum consciousness state • **During chronic phase** (< 3 months after stroke) repeated medical complications (or severe post-stroke dementia)
Chronic Neurological Diseases: Motor neuron, MS, ALS, Parkinson	• **Progressive decline of physical functional and/or cognitive functions** • Complex or resistant **symptoms** • **Persistent dysphagia** • **Increasing communication difficulties** • **Frequent aspiration pneumonias,** dyspnea or respiratory failure
Chronic Liver Disease	• **Advanced cirrosis** Child C. stage (determined without complications or having treated and optimised treatment), MELD-Na >30 or refractory ascites, hepato-renal syndrome and/or high digestive bleeding despite treatment. • **Hepatic carcinoma** stage C or D
Chronic Renal Disease	• **Severe renal failure** (GF < 15), in no target patients or not accepting transplant, sustitutive treatment or dialysis • End of dialysis or transplant failure

(1) Use validated tools for severity and/or prognosis according to experience and evidence. (2) In all cases, assess emotional distress or functional impact in patients (and family) as criteria of palliative needs. (3) In all cases, assess ethical dilemas in decisión-making. (4) Always include association with multimorbidity.

HOW TO IMPROVE CARE TOWARD IDENTIFI

Actions	Recomm
1. Multidimensional assessment of situation and start of integrated person-centred care	Explore all tools Start integ Assess care
2. Explore patients' (and families) values, preferences and worries	Gradually s
3. Revise illness/condition status	Revise stat Recommen Bear in mi aspects
4. Revise treatment	Update ob therapeuti
5. Identify and take care of main caregiver	Needs and grief risk),
6. Involve healthcare team and identify responsible	In: Evaluat
7. Define, share and start Comprehensive and Multidimensional Therapeutic Plan	Respecting care, involv
8. Integrated Care: Organize care provision with all services involved with particular focus on defining the role of the specific palliative care and emergency services	Start case pathways services, in
9. Registry and share relevant clinical information with all services involved	Shared clin
10. Assess, review and monitor results	Frequent re

ED PATIENTS?

endations
dimensions (physical, emotional, social and spiritual) with validated rated care process egivers' needs
start Advance Care Planning
us, prognostic, objectives, possible complications ndations for prevention and response to crisis nd static (severity) and dynamic (evolution or progression in time)
jectives, therapeutic adjustment, apply de-prescribing if necessary, c conciliation among services
demands: Assessment (caring capacity, adjustment, complicated Education and support, Empowerment
ion, Therapeutic Plan, Roles Definition in follow-up and emergency care
g patients' preferences, managing all dimensions, using the square of ving teams
management and preventive care, shared-decisions process, care between services, organizing transitions, building consensus among volve patients in the proposals
ical charts, sessions
eviews and updates, audit post-care, generate evidence

HOW TO IMPROVE PALLIATIVE CARE IN HEALTH AND SOCIAL SERVICES?

There are persons with palliative care needs in different proportions in most health services.

Prevalence in our context

1.3-1.5% General Population (depends on ageing rate)
1% population taken care by primary care teams
40% in acute hospitals
70% in socio-health/intermediate centres
30-70% in residence / hospice

This fact shows the relevance (quantitative and qualitative) and the need of facing this challenge with a systematic approach.

Measures to improve palliative care
1. To design, establish and protocol a formal proposal for palliative care improvement
2. To determine prevalence and identify persons with palliative care needs with validated instruments
3. To establish protocols, registries and instruments based on evidence to assess patients' needs and respond to the most prevalent ones
4. To train healthcare professionals in palliative care (communication, advance care planning, symptom control, etc.)
5. To identify main caregivers and offer them support and education, including grief care
6. To increase team work (share evaluation, define objectives and follow-up)
7. In services with high prevalence, designate specific professionals (referents) with advanced or intermediate education and specific settings for palliative care (home care, outpatients, individual rooms)
8. To increase offer and intensity of caring focused on improving identified patients' quality of life (planned care, accessibility, crisis prevention, continuous and urgent care)
9. Integrated care: to establish care pathways, intervention criteria for conventional and specific services, to define roles in conventional, continuous and urgent care, to coordinate and share information among settings
10. To take into account and respond to ethical challenges of timely identification: to promote benefits and reduce risks and guarantee patients' rights