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© 3.0 (2016)

Xavier Gómez-Batiste, Marisa Martínez-Muñoz, Carles Blay, Jordi Amblàs, Laura Vila, Xavier Costa, Joan Espaulella, Jose Espinosa
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.

The NECPAL CCOMS-ICO© tool has been developed and validated to identify these patients effectively. It has been revised by the Catalan Committee of Bioethics (Spain). According to the experience acquired, and with International cooperation, we have introduced some elements for improvement.

To cite: Xavier Gómez-Batiste, Marisa Martínez-Muñoz, Carles Blay et al. 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© 3.0. (2016). Accessible at:

Utilities

| 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 the right to receive a comprehensive and integrated care.

• 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.

• 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).
**Considerations to bear in mind**

- The Surprise question and the other parameters must act as an “trigger” of a “palliative approach” starting a “reflexive process”

- The gradual insertion of this “palliative approach” must be compatible, inclusive, and synchronic with treatments focused in the control of illnesses, and curative approach of concurrent processes, avoiding dichotomist approaches

- 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 relation with the risk on mortality, the aim of the tool is not to establish prognosis, and these utility must be used with caution, to insert a “prognostic approach” or “vision”.

**Ethical aspects of timely identification**

- Timely identification aims an actively improving the quality of care through inserting a palliative approach, which has shown benefits for patients

- It promotes equity, coverage, access, and the exercise of the autonomy of patients.

- There are risks related to the stigmatization, losing curative opportunities, or the negative impact in patients, which can be substantially reduced with the explicit and accessible clinical information, the active participation of patients, the training of all professionals, the adoption of quality improvement measures, and the participation of the ethical committees in its implementation.
HOW TO USE THE NECPAL-CCOMS-ICO© TOOL VERSION 3.0 2016

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”: with severe impact, progression, polypharmacy, multimorbidity, 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

• Professionals: doctors and nurses knowing the patient’s evolution

• Setting: any service of the system (not recommendable in emergency wards not knowing the patient, or in wards before 3 days of admission)

• Requisites: knowing the patient and the evolution

• Use clinical criteria and parameters (no need of other complementary explorations)

• Recommended interdisciplinary (doctor and nurse, with the participation of other professionals)
| Surprise Question (to/among professionals) | Would you be surprised if this patient dies within the next year? | No (+) Yes (-)
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>“Demand” or “Need”</td>
<td>- Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort?</td>
<td>Yes / No</td>
</tr>
<tr>
<td></td>
<td>- Need: identified by healthcare professionals from the team</td>
<td>Yes / No</td>
</tr>
<tr>
<td>General Clinical Indicators: 6 months</td>
<td>- Nutritional Decline</td>
<td>Weight loss &gt; 10%</td>
</tr>
<tr>
<td></td>
<td>- Functional Decline</td>
<td>Karnofsky or Barthel score &gt; 30%</td>
</tr>
<tr>
<td></td>
<td>- Cognitive Decline</td>
<td>Minimental/Pfeiffer Decline</td>
</tr>
<tr>
<td>Severe Dependence</td>
<td>Karnofsky &lt;50 o Barthel &lt;20</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Geriatric Syndromes</td>
<td>- Falls</td>
<td>Pressure Ulcers</td>
</tr>
<tr>
<td>Persistent symptoms</td>
<td>Pain, weakness, anorexia, dyspnoea, digestive...</td>
<td>Symptom Checklist (ESAS)</td>
</tr>
<tr>
<td>Psychosocial aspects</td>
<td>Distress and/or Severe adaptive disorder</td>
<td>Detection of Emotional Distress Scale (DME) &gt; 9</td>
</tr>
<tr>
<td>Severe Social Vulnerability</td>
<td>Social and family assessment</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Multi morbidity</td>
<td>&gt;2 chronic diseases (from the list of specific indicators)</td>
<td>Charlsson Test</td>
</tr>
<tr>
<td>Use of resources</td>
<td>Evaluate Demand/intensity of interventions</td>
<td>&gt; 2 urgent or not planned admittances in last 6 months</td>
</tr>
<tr>
<td>Specific indicators</td>
<td>Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced</td>
<td>To be developed as annexes</td>
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**Classification:**

- **SQ**: + “I wouldn’t be surprised if...”  
- “I would be surprised if...”

- **NECPAL**: – (negative) or + (positive if there are additional parameters) / 1+, 2+, 3+, ..., ..., ..., 13+

**Codification and Registry:**

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

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<tr>
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<th>Codification</th>
<th>Registry</th>
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| SQ: + “I wouldn’t be surprised if...” | - Codification: A specific code, as “Advanced chronic patient”, should be used, as opposed to the common ICD9 V66.7 or ICD10 Z51.5 | Clinical Charts: After the surprise question, the different parameters should be explored, and add + according to the positive found (NECPAL +, or ++, or ++++, or ++++++++++++)
| SQ- = “I would be surprised if...”   | - Registry   | Shared Clinical Chart: match codification and registry of additional relevant clinical information that describes the situation and recommendations for care in specific scenarios |

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<th>Recommendations</th>
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| **1. Multidimensional assessment of situation and start of integrated person-centred care** | Explore all dimensions (physical symptoms, emotional, social, spiritual, ...) with validated tools  
Start integrated care process  
Assess caregivers’ needs                                                                 |
| **2. Explore values, preferences and worries of patients and families**   | Gradually start Advance Care Planning                                                                                                                                                                               |
| **3. Revise illness/condition status**                                  | Revise status, prognostic, objectives, possible complications  
Recommendations for prevention and response to crisis  
Bear in mind static (severity) and dynamic (evolution or progression) aspects |
| **4. Revise treatment**                                                 | Update objectives, therapeutic adjustment, de-prescribing if necessary, therapeutic conciliation among services |
| **5. Identify and take care of main caregiver**                        | Needs and demands: Assessment (caring capacity, adjustment, complicated grief risk), Education and support, Empowerment                                                                                          |
| **6. Involve team and identify responsible**                           | In: Evaluation, Therapeutic Plan, Roles Definition in follow-up and emergency care                                                                                                                                   |
| **7. Define, share and start Comprehensive and Multidimensional Therapeutic Plan** | Respecting patients’ preferences, managing all dimensions, using the square of care, involving teams                                                                                                                |
| **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 management and preventive care, shared-decisions process, care pathways between services, organizing transitions, building consensus among services, involve patients in the proposals |
| **9. Registry and share relevant clinical information with all services involved** | Shared clinical charts, sessions                                                                                                                                                                                   |
| **10. Assess, review and monitor results**                             | Frequent reviews 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 of the 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 of 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 the 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 or advanced intermediate education and specific timeframes 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 guaranteeing the patients’ rights
RECENT REFERENCES


## Specific NECPAL Criteria Severity / Progression / Advanced Disease

### Cancer
- **Metastatic** or advanced locoregional **Cancer** in progression
- **Persistent or uncontrolled** or refractory **Symptoms** despite treatment

### Chronic Lung Disease
- Shortness of breath at rest on minimal exertion
- Confined to home with severe limitation
- **Spirometric Criteria** of severe obstruction (VEMS <30%) or criteria severe restrictive (CV <40%/DLCO <40%)
- **Gasometric Criteria** chronic oxygen therapy at home
- Need of continuous corticotherapy
- Associated **Symptomatic Heart Failure**

### Chronic Heart Disease
- Shortness of breath at rest on minimal exertion
- **Heart failure** NYHA estadi III or IV, non-surgical severe valvular disease or nonsurgical advanced coronary disease
- **Ecocardiography** basal: FE <30% o HTPA severe (PAPs > 60)
- Associated **Renal failure** (FG <30 l/min)

### 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)
- In acute phase (< 3 months after stroke): low consciousness state
- In chronic phase (< 3 months after stroke) **repeated medical complications** (or severe dementia)

### Chronic Neurological Diseases: Motor neuron, MS, ALS, Parkinson
- Progression of functional, nutritional, and/or cognitive declines
- Complex or resistant symptoms
- Persistent dysphagia
- Increasing communication difficulties
- Frequent aspiration pneumonias, dyspnea or respiratory failure

### Chronic Liver Disease
- **Advanced cirrhosis** Child C. Refractory ascites, hepatorenal syndrome and/or upper digestive bleeding despite treatment.
- **Hepatic carcinoma** stage C or D

### Chronic Renal Disease
- **Severe renal failure** (GF <15), patients with no indication or not accepting transplant or dialysis
- End of dialysis or transplant failure

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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 a criteria of palliative needs
3. In all cases, assess ethical dilemmas in decision-making
4. Include always association with multimorbidity
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Introduction

Recent references


**NECPAL CCOMS-ICO® TOOL VERSION 3.0 2016 ENG**

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Print version
Size of the document unfolded 315 x 297 (double-side printed)
Size of the folded document: 105x148 mm

STEP 1

STEP 2

STEP 3