Online supplement 1

European Respiratory Society Clinical Practice Guideline:

Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease

PICO questions and outcomes
In- and exclusion criteria for each question
### Question 3 (PICO). Palliative care interventions for people with COPD

**PICO question:**

*In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (compared to palliative care interventions not involving informal caregivers or no palliative care interventions)*

<table>
<thead>
<tr>
<th>Population</th>
<th>People with COPD and their informal caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>Palliative care involving informal caregivers</td>
</tr>
<tr>
<td>Comparison</td>
<td>Palliative care not involving informal caregivers or no palliative care intervention</td>
</tr>
</tbody>
</table>

#### Critical Outcomes
1. Communication within the family and/or with healthcare professionals
2. Anxiety of informal caregivers
3. Anxiety of people with COPD
4. Burden / stress for informal caregivers
5. Depression of the informal caregiver
6. Depression of people with COPD
7. Quality of life / well-being of informal caregivers
8. Quality of life / well-being of people with COPD
9. Grief/ bereavement/ Loss experienced by informal caregivers
10. Breathlessness of people with COPD

#### Outcomes not critical and therefore not assessed
- Family adjustment to illness; Coping; Informal caregiver preferences regarding palliative care; Communication within the family and/or with healthcare professionals; Knowledge about the disease of the informal caregiver; Knowledge about the disease of the person with COPD; Connectedness/Intimacy with the partner; Satisfaction of the informal caregiver with the palliative care intervention; Satisfaction of the person with COPD with the palliative care intervention; Personal growth of the informal caregiver; Personal growth of the person with COPD; Stress of...
the person with COPD; Fatigue of the informal caregivers; Fatigue of the person with COPD; Loneliness of the informal caregiver; Loneliness of the person with COPD; Grief/ bereavement/Loss experienced by the person with COPD.

**Detailed description of informal caregiver:**

Informal caregivers (any relative, partner, friend, neighbor, or significant other with personal relationship with the person cared for and who provides a broad range of unpaid assistance to the person with COPD or ILD[1]) have a major and complex role. They fulfill many tasks, including: managing and monitoring medication, appointments, and symptoms; ensuring hygiene and nutritional needs are met; encouraging and supporting adherence to treatment recommendations; providing physical, social, psychological and emotional support; recognizing and managing emergency issues; handling equipment; managing care recipient behavior and temperament; handling household- and illness-related finances; and carrying out decision-making and problem-solving.[2-8] They are therefore the main, although often “hidden”, workforce responsible for providing most of daily care.[9] Nevertheless, their different roles require health literacy, disease knowledge, financial security, household conditions, psychological readiness, medical care abilities, among others and yet they generally receive insufficient support.[2-5, 10]

**References**


Question 4 (PICO). Palliative care interventions for people with ILD

PICO question:

*In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (compared to palliative care interventions not involving informal caregivers or no palliative care interventions)*

<table>
<thead>
<tr>
<th>Population</th>
<th>People with ILD and their informal caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>Palliative care involving informal caregivers</td>
</tr>
<tr>
<td>Comparison</td>
<td>Palliative care not involving informal caregivers or no palliative care intervention</td>
</tr>
<tr>
<td>Critical outcomes</td>
<td>1. Communication within the family and/or with healthcare professionals</td>
</tr>
<tr>
<td></td>
<td>2. Anxiety of informal caregivers</td>
</tr>
<tr>
<td></td>
<td>3. Anxiety of people with ILD</td>
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<tr>
<td></td>
<td>4. Burden / stress for informal caregivers</td>
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<tr>
<td></td>
<td>5. Depression of the informal caregivers</td>
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<tr>
<td></td>
<td>6. Depression of people with ILD</td>
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<tr>
<td></td>
<td>7. Quality of life / well-being of the informal caregivers</td>
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<tr>
<td></td>
<td>8. Quality of life / well-being of people with ILD</td>
</tr>
<tr>
<td></td>
<td>9. Grief/ bereavement/loss experienced by the informal caregivers</td>
</tr>
<tr>
<td></td>
<td>10. Breathlessness of people with ILD</td>
</tr>
</tbody>
</table>
| Outcomes not critical and therefore not assessed | Family adjustment to illness; Coping; Informal caregiver preferences regarding palliative care; Communication within the family and/or with healthcare professionals; Knowledge about the disease of the informal caregiver; Knowledge about the disease of the person with ILD; Connectedness/Intimacy with the partner; Satisfaction of the informal caregiver with the palliative care intervention; Satisfaction of the person with ILD with the palliative care intervention; Personal growth of the informal caregiver; Personal growth of the person with ILD; Stress of the...
person with ILD; Fatigue of the informal caregivers; Fatigue of the person with ILD; Loneliness of the informal caregiver; Loneliness of the person with ILD; Grief/ bereavement/Loss experienced by the person with ILD.
Question 5 (PICO). Advance care planning interventions for people with COPD

PICO question:
In people with COPD, should Advance Care Planning (ACP) interventions be used? (compared with no or unstructured forms of advance care planning)

<table>
<thead>
<tr>
<th>Population</th>
<th>People with COPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>Advance care planning (ACP)</td>
</tr>
<tr>
<td>Comparison</td>
<td>No or unstructured forms of ACP</td>
</tr>
<tr>
<td>Critical outcomes</td>
<td>1. Quality of communication between people with COPD and healthcare professionals</td>
</tr>
<tr>
<td></td>
<td>2. Concordance between the wishes of the person with COPD and received care at the end of life</td>
</tr>
<tr>
<td></td>
<td>3. Documented discussions between informal caregivers and health professional about goals of care / advance care planning</td>
</tr>
<tr>
<td></td>
<td>4. Symptom control at the end of life</td>
</tr>
<tr>
<td></td>
<td>5. Experience of end of life care</td>
</tr>
<tr>
<td></td>
<td>6. Avoidable hospital visits near end of life, measured by emergency department attendance without admission</td>
</tr>
<tr>
<td></td>
<td>7. Informal caregivers’ satisfaction with end of life care</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Use of interventions with main aim to prolong life; Place of death</td>
</tr>
<tr>
<td>not critical</td>
<td>according to the wish of the person with COPD; Caregiver’s experience of end-of-life care; Length of stay in hospital; Concordance in wishes</td>
</tr>
<tr>
<td>and</td>
<td>between surrogates and persons with COPD; Awareness among</td>
</tr>
<tr>
<td>therefore</td>
<td>healthcare providers of preferences of people with COPD during end of life and advance decisions.</td>
</tr>
</tbody>
</table>
Question 6 (PICO). Advance care planning interventions for people with ILD

PICO question:

*In people with ILD, should Advance Care Planning (ACP) interventions be used? (compared with no or unstructured forms of advance care planning)*

<table>
<thead>
<tr>
<th>Population</th>
<th>People with ILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>Advance care planning (ACP)</td>
</tr>
<tr>
<td>Comparison</td>
<td>No or unstructured forms of ACP</td>
</tr>
</tbody>
</table>

**Critical outcomes**

1. Quality of communication between person with ILD and healthcare professionals
2. Concordance between the wishes of the person with ILD and received care at the end of life
3. Documented discussions between informal caregivers and health professional about goals of care / advance care planning
4. Symptom control at the end of life
5. Experience of end of life care
6. Avoidable hospital visits near end of life, measured by emergency department attendance without admission
7. Informal caregivers’ satisfaction with end of life care

**Outcomes not critical and therefore not assessed**

- Use of interventions with main aim to prolong life; Place of death according to the wish of the person with ILD; Caregiver’s experience of end-of-life care; Length of stay in hospital; Concordance in wishes between surrogates and persons with ILD; Awareness among healthcare providers of preferences of people with ILD during end of life and advance decisions.
In- and exclusion criteria for each question

**Question 1**

*Inclusion criteria question 1*
- Providing a definition concerning palliative care applicable for people with COPD or ILD
- Systematic review or original study

*Exclusion criteria question 1*
- Letter, protocol or editorial
- Addressing only terminal care
- Addressing only persons with cancer

**Question 2**

*Inclusion criteria question 2*
- Studies including people with COPD or ILD, caregiver(s), or clinicians providing care for these groups
- Studies reporting on referral criteria, indicators, triggers to start palliative care (generalist or specialist)
- Studies of tools used to screen for and/or assess palliative care needs
- Studies of palliative care interventions (described by authors or fitting definition text)
- Systematic review, clinical trial, observational study, interview/focus groups, case series
- Published in any language

*Exclusion criteria question 2*
- Studies reporting symptoms without an explicit link to palliative care
- Studies including only caregiver(s) (e.g., starting bereavement care)
- Study protocols
- Opinion pieces including narrative reviews, editorials, correspondence.
- Single case studies

**Question 3**

*Inclusion criteria question 3*
- Studies including palliative care interventions involving informal caregivers of adult people with COPD
- Systematic review or original study
- No language restriction

**Exclusion criteria question 3**

- Studies reporting on measurement properties of tools designed to measure effects of the palliative care interventions
- Interventions targeting only formal caregivers in palliative care
- Studies reporting only on advance care planning interventions involving informal caregivers
- Studies not reporting outcomes of interventions (e.g., protocols, design of study or development intervention etc)
- Case reports

**Question 4**

**Inclusion criteria question 4**

- Studies including palliative care interventions involving informal caregivers of adult people with ILD
- Systematic review or original study
- No language restriction

**Exclusion criteria question 4**

- Studies reporting on measurement properties of tools designed to measure effects of the palliative care interventions
- Interventions targeting only formal caregivers in palliative care
- Studies reporting only on advance care planning interventions involving informal caregivers
- Studies not reporting outcomes of interventions (e.g., protocols, design of study or development intervention etc)
- Case reports

**Question 5**

**Inclusion criteria question 5**

- Studies regarding effects of advance care planning (ACP) on people with chronic obstructive pulmonary disease (COPD)
- Adult people or their representatives
- ACP defined as intervention labelled as ACP by the authors or intervention involving any of:
  - Discussion of values and goals of people with COPD for future medical care and treatment
- Clarifying values and goals of people with COPD for future medical care and treatment
- Documenting wishes of people with COPD
  - Data are presented specifically for ACP and COPD:
  - In case of complex interventions, it must include and report separate data for ACP
  - In case of mixed samples, it must report separate data for COPD
  - Published work without restriction of year of publication and language

**Exclusion criteria question 5**
- Studies not reporting outcomes of ACP (e.g., protocols, design of study or development intervention, etc)
- Only abstract published
- Case studies
- Review studies

**Question 6**

**Inclusion criteria question 6**
- Studies regarding effects of advance care planning (ACP) on people with Interstitial Lung Disease (ILD)
- Adult people with ILD or their representatives
- ACP defined as intervention labelled as ACP by the authors or intervention involving any of:
  - Discussion of values and goals of people with ILD for future medical care and treatment
  - Clarifying values and goals of people with ILD for future medical care and treatment
  - Documenting wishes of people with ILD
- Data are presented specifically for ACP and ILD:
  - In case of complex interventions, it must include and report separate data for ACP
  - In case of mixed samples, it must report separate data for ILD
  - Published work without restriction of year of publication and language

**Exclusion criteria question 6**
- Studies not reporting outcomes of ACP (e.g., protocols, design of study or development intervention, etc)
- Only abstract published
- Case studies
- Review studies
Question 7 and 8

Inclusion criteria question 7 and 8

- Systematic reviews or original studies evaluating implementation of palliative care within routine clinical care for people with COPD or ILD and their informal caregivers
- Systematic reviews or original studies evaluating strategies for implementing ACP in routine clinical care for people with COPD and ILD
- In case of mixed samples, it must include people with COPD or ILD and report data relevant to those groups
- Published work without restriction of year of publication and language

Exclusion criteria question 7 and 8

Systematic reviews:

- Generic systematic review, no or limited COPD-specific data
- Highlights needs but no insights into improved care
- Not a systematic review (e.g., clinical review; overview of existing guidelines)
- Not addressing palliative care

Other articles

- No insights into improved care (e.g., description of living with COPD; surveys shortcomings)
- Generic, no insights relevant to COPD or ILD services
- Prediction of mortality post-admission
- Clinical review/perspective
- Protocol, trial registration
- Conference abstract