**This document/ pages contains the supplementary information.**

**Table A**
Criteria listed in the guideline: Palliative care in COPD, written by the organization ‘Palliative care in the Netherlands’

|  |  |
| --- | --- |
| **Item** | **Criteria** |
| 1 | A negative response to the surprise question “Would you be surprised if this patient died within the next 12 months?” |
| 2 | The presence of comorbidity |
| 3 | The presence of underweight |
| 4 | A poor physical condition,  |
| 5 | The presence of dyspnea |
| 6 | Reaching disease-related milestones (e.g., losing a job due to COPD, hospitalization with ventilation, rejection for lung transplantation or bronchoscopic or surgical procedures to reduce hyperinflation, need to make adjustments to your home due to COPD, or overburdened caregiver) |
| 7 | Long-term oxygen therapy (LTOT) |
| 8 | Forced expiratory volume in 1 second (FEV1) <30% predicted  |
| 9 | One or more hospitalizations per year due to an exacerbations of COPD,  |
| 10 | Physical, psychological, social, or spiritual discomfort that is unacceptable to the patient despite optimal disease-oriented treatment and also leads to a decrease in quality-of-life  |

**Table B**
Individual palliative care needs after merging and duplicate removal (N=63)

|  |  |  |  |
| --- | --- | --- | --- |
| **Item** | **Individual palliative care needs** | **Theme** | **Authors** |
| 1 | Physical limitation due to physical complains | Physical care needs | Clari et al., 2018; Gardener et al., 2018. |
| 2 | Impact of COPD on ADL | Physical care needs | Clari et al., 2018; Gardener et al., 2018. |
| 3 | LTOT during physical activity | Physical care needs | Clari et al., 2018; Gardener et al., 2018. |
| 4 | Caregiver support in physical activity or during physical complains | Physical care needs | Ferreira et al., 2020. |
| 5 | Psychological complaints such as gloom, panic, anxiety, irritability, worrying | Psychological care needs | Crawford et al., 2013. |
| 6 | Feelings of low self-worth, sadness, and lack of confidence | Psychological care needs | Gardener et al., 2018. |
| 7 | Dealing with thoughts about suicide | Psychological care needs | Bolton et al., 2022. |
| 8 | Try to bring joy and happiness to the patient  | Psychological care needs | Ferreira et al., 2020. |
| 9 | Loneliness, social isolation | Social care needs | Clari et al., 2018; Crawford et al., 2013. |
| 10 | Limited social and activity engagement, limited contribution to society | Social care needs | Clari et al., 2018; Bolton et al., 2022. |
| 11 | Impact of COPD in the patients social life (e.g., physical boundaries) | Social care needs | Clari et al., 2018; Gardener et al., 2018. |
| 12 | Adapting social contact in order to maintain relationships (including the caregiver) | Social care needs  | Bolton et al., 2022. |
| 13 | Support in coping with a loss of intimacy | Social care needs  | Bolton et al., 2022. |
| 14 | Emotional complaints associated with the course of the disease (denial, diagnosis, exacerbation, breathlessness) | Emotional needs | Clari et al., 2018; Bolton et al., 2022; Gardener et al., 2018; Ferreira et al., 2020. |
| 15 | Emotional complaints associated with the usage of medical therapies or care dependence (e.g., LTOT) | Emotional needs | Clari et al., 2018; Bolton et al., 2022, |
| 16 | Emotional complaints associated with an identity change | Emotional needs | Clari et al., 2018; Bolton et al., 2022; Ferreira et al., 2020, |
| 17 | Emotional complaints associated with Isolation | Emotional needs | Clari et al., 2018. |
| 18 | Support in overcoming feelings that you are alone in having COPD | Emotional needs | Clari et al., 2018; Bolton et al., 2022. |
| 19 | Support with psychologically pessimism and preventing pessimism | Emotional needs | Gardener et al., 2018. |
| 20 | Overcoming guilt, letting go lack of sympathy for ''self-inflicted'' condition | Emotional needs | Gardener et al., 2018; Crawford et al., 2013. |
| 21 | Questions about the purpose of life  | Spiritual care needs | Bolton et al., 2022. |
| 22 | Dealing with the feeling of being 'just an existence' and unusefulness | Spiritual care needs  | Bolton et al., 2022. |
| 23 | Support in creating feeling of rewards in life | Spiritual care needs  | Bolton et al., 2022. |
| 24 | Maintaining optimism | End of life care needs | Clari et al., 2018; Crawford et al., 2013. |
| 25 | Problems related to finding and using financial and legal services | Financial care needs | Gardener et al., 2018. |
| 26 | Experiencing financial pressure caused by COPD | Financial care needs | Clari et al., 2018; Crawford et al., 2013. |
| 27 | Questions about medication, treatments and side effects.  | Medication/ Therapy  | Gardener et al., 2018. |
| 28 | The need to (re)discuss worries about medication and treatments | Medication/ Therapy  | Gardener et al., 2018. |
| 29 | Information about LTOT, nebulizers and inhalers (incl physical and social limitations due to LTOT) | Medication/ Therapy  | Gardener et al., 2018; Crawford et al., 2013. |
| 30 | Being aware of the diagnosis COPD, and having greater clarity about COPD | Patient information needs | Gardener et al., 2018. |
| 31 | Support in understanding COPD, particularly its progressive and terminal nature | Patient information needs | Clari et al., 2018; Crawford et al., 2013; Gardener et al., 2018. |
| 32 | Being familiar with terminology (such as COPD and emphysema) | Patient information needs | Clari et al., 2018; Gardener et al., 2018. |
| 33 | Worries about the informal caregivers burden | Informal caregiver needs | Ferreira et al., 2020. |
| 34 | Information needs of the informal caregiver | Informal caregiver needs | Gardener et al., 2018; Crawford et al., 2013. |
| 35 | The informal caregiver needs support | Informal caregiver needs | Gardener et al., 2018; Crawford et al., 2013. |
| 36 | Lack of respite care | Informal caregiver needs | Crawford et al., 2013. |
| 37 | Emotional coping for informal caregivers in dealing with the symptoms of COPD (such as breathlessness) | Informal caregiver needs | Ferreira et al., 2020. |
| 38 | Restriction of independence, own daily activities | Informal caregiver needs | Ferreira et al., 2020. |
| 39 | Worries about direct available care in case of acute deterioration (Inc. after working hours) | Collaborating with HCP | Gardener et al., 2018; Bolton et al., 2022. |
| 40 | Coordination of care (incl. fragmentation) | Collaborating with HCP | Clari et al., 2018; Crawford et al., 2013. |
| 41 | Accessibility of HCP  | Collaborating with HCP | Clari et al., 2018; Crawford et al., 2013; Gardener et al., 2018. |
| 42 | Follow-up after hospital | Collaborating with HCP | Clari et al., 2018; Crawford et al., 2013. |
| 43 | Communication with and between HCP | Collaborating with HCP | Clari et al., 2018; Crawford et al., 2013. |
| 44 | Access to community services | Collaborating with HCP | Clari et al., 2018; Crawford et al., 2013. |
| 45 | Limited involvement of palliative care services | Collaborating with HCP | Crawford et al., 2013. |
| 46 | Pulmonary rehabilitation access very limited and often too late | Collaborating with HCP | Crawford et al., 2013.. |
| 47 | Negative attitude of HCPs about smokers | Collaborating with HCP | Crawford et al., 2013 |
| 48 | Information and discussing future wishes and palliative care in COPD | ACP needs | Clari et al., 2018; Gardener et al., 2018; Crawford et al., 2013; Ferreira et al., 2020. |
| 49 | Creating a clear image about the terminal aspect of COPD, the provision of palliative care and death | ACP needs | Clari et al., 2018; Ferreira et al., 2020; Crawford et al., 2013. |
| 50 | Uncertainty about timing of ACP discussions | ACP needs | Crawford et al., 2013. |
| 51 | Uncertainty about whose role it is to raise ACP | ACP needs | Crawford et al., 2013. |
| 52 | Needs concerning life-sustaining treatments, end of life care, role of the legal representative, and funeral arrangements | ACP needs | Crawford et al., 2013; Gardener et al., 2018. |
| 53 | Preferences about how, when and with whom information can be shared and discussed related to life-sustaining treatments/ end of life care | ACP needs | Gardener et al., 2018. |
| 54 | Accessibility to devices that increase mobility and independence | Getting out and about needs | Gardener et al., 2018. |
| 55 | Promotion of devices that increase mobility and independence | Getting out and about needs | Gardener et al., 2018. |
| 56 | Support in maintaining or (re)discovering hobbies  | Getting out and about needs | Bolton et al., 2022; |
| 57 | The utility of self-management | Disease management | Crawford et al., 2013; Gardener et al., 2018. |
| 58 | Information about management of COPD (incl. exacerbations) | Disease management | Gardener et al., 2018; Ferreira et al., 2020. |
| 59 | Support in applying self-management in order to maintain independence | Disease management | Gardener et al., 2018. |
| 60 | Support in maintaining self-management during critical care moments (incl. breathlessness) | Disease management | Gardener et al., 2018. |
| 61 | Support in lifestyle changes (exercising/ diet) | Healthy Lifestyle | Gardener et al., 2018. |
| 62 | Support during smoking cessation, including accessibility  | Healthy Lifestyle | Gardener et al., 2018; Crawford et al., 2013. |
| 63 | Opportunities to discuss lifestyle choices in a non-judgmental context | Healthy Lifestyle | Gardener et al., 2018. |

**Table C**
Composition of palliative care themes (N=25)

|  |  |  |  |
| --- | --- | --- | --- |
| **Item** | **Needs** | **Themes** | **Authors** |
| 1 | Physical limitation due to physical complains | Physical care needs | Clari et al., 2018; Gardener et al., 2018. |
| 2 | The need of LTOT during physical activity | Physical care needs | Clari et al., 2018; Gardener et al., 2018. |
| 3 | Feelings of low self-worth, gloom, anxiety, lack of confidence, and hopelessness  | Psychological care needs | Crawford et al., 2013; Gardener et al., 2018; Bolton et al., 2022. |
| 4 | Loneliness, social isolation, limited social and activity engagement, limited contribution to society | Social care needs | Clari et al., 2018; Crawford et al., 2013. |
| 5 | Impact of COPD in the patients social life (e.g., changing relationships) | Social care needs | Clari et al., 2018; Gardener et al., 2018; Bolton et al., 2022. |
| 6 | Emotional complains associated with the course of the disease (denial, diagnosis, guilt, exacerbation, breathlessness) | Emotional needs | Clari et al., 2018; Bolton et al., 2022; Gardener et al., 2018; Ferreira et al., 2020; Crawford et al., 2013. |
| 7 | Emotional complains associated with the usage of medical therapies or care dependence (e.g., LTOT) | Emotional needs | Clari et al., 2018; Bolton et al., 2022. |
| 8 | Emotional complains associated with an identity change due to COPD | Emotional needs | Clari et al., 2018; Bolton et al., 2022; Ferreira et al., 2020. |
| 9 | Questions about the purpose of life and spiritual needs  | Spiritual care needs | Bolton et al., 2022. |
| 10 | Maintaining optimism | End-of-life care needs | Clari et al., 2018; Crawford et al., 2013; Ferreira et al., 2020. |
| 11 | Problems related to finding and using financial and legal services | Financial care needs | Gardener et al., 2018; Clari et al., 2018; Crawford et al., 2013. |
| 12 | Questions or worries about medication, treatments and side effects. (Incl LTOT, inhalers and nebulizers) | Medication/ Therapy needs | Gardener et al., 2018; Crawford et al., 2013. |
| 13 | Support in understanding COPD, particularly its progressive and terminal nature | Patient information needs | Clari et al., 2018; Crawford et al., 2013; Gardener et al., 2018. |
| 14 | Being familiar with terminology (such as COPD and emphysema) | Patient information needs | Clari et al., 2018; Gardener et al., 2018. |
| 15 | Information needs of the informal caregiver | Informal caregiver needs | Gardener et al., 2018; Crawford et al., 2013; Ferreira et al., 2020. |
| 16 | Support of the informal caregiver in providing care, including support in worries  | Informal caregiver needs | Gardener et al., 2018; Crawford et al., 2013; Ferreira et al., 2020. |
| 17 | Worries about direct available care in case of acute deterioration (Inc. after working hours) | Collaborating with HCP | Gardener et al., 2018; Bolton et al., 2022. |
| 18 | Coordination of care (incl. fragmentation) and involvement of palliative care services  | Collaborating with HCP | Clari et al., 2018; Crawford et al., 2013; Gardener et al., 2018. |
| 19 | Needs concerning life sustaining treatments, end of life care, role of the legal representative, and funeral arrangements | ACP needs | Crawford et al., 2013; Gardener et al., 2018. |
| 20 | Preferences about how, when and with whom future care wishes can be discussed related | ACP needs | Clari et al., 2018; Gardener et al., 2018; Crawford et al., 2013; Ferreira et al., 2020. |
| 21 | Accessibility to devices that increase mobility and independence | Getting out and about  | Gardener et al., 2018. |
| 22 | Support in maintaining or (re)discovering hobbies  | Getting out and about needs | Bolton et al., 2022. |
| 23 | The utility of self-management | Disease management | Crawford et al., 2013; Gardener et al., 2018. |
| 24 | Support in applying self-management in order to maintain independence | Disease management | Gardener et al., 2018; Ferreira et al., 2020. |
| 25 | Opportunities to discuss lifestyle choices in a non-judgmental context | Healthy Lifestyle | Gardener et al., 2018;Crawford et al., 2013. |

**Table D**
Palliative care themes discussed during the parallel focus groups (N=20)

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Item  | Theme | In the original ‘I-HARP’ (Ament et al., 2020) | Signaling question | Parallel Focus Groups |  |  |  |  | Inclusion criteria |  |  | Test version ‘I-HARP for COPD’ |
|  |  |  |  | Prioritized in focus group 1 | Prioritized in focus group 2 | Prioritized in focus group 3 | Prioritized in focus group 4 | Prioritized in focus group 5 | Selected at least twice in a parallel focus group | Include the four palliative care domains | Include attention for the informal caregiver | Selected |
| 1. | Physical needs  | X | Do you have any physical complains that make it more difficult for you to do normal activities? |  | X | X | X | X | X | X |  | Yes, as number 1 |
| 2. | Physical needs during activity | X | Do you need help or more help with washing yourself, getting dressed, doing shopping, or doing housework? |  | X | X | X |  | X |  |  | Yes, as number 2 |
| 3. | Patient information needs  | X | Do you have any questions about COPD or your treatment? | X | X | X |  | X | X |  |  | Yes, as number 3 |
| 4. | Care needs related to grief and lost | X | COPD can considerably affect your daily life. Do you find it difficult to cope with? | X | X | X | X | X | X |  |  | Yes, as number 4 |
| 5. | Psychosocial needs | X | Many people with COPD experience psychological complains. Does this also apply to you? | X | X | X | X | X | X | X |  | Yes, as number 5 |
| 6. | Social needs | X | Do you sometimes feel misunderstood by important people who are close to you? | X |  |  | X | X | X | X |  | Yes, as number 6 |
| 7. | Spiritual needs  | X | Would you like to talk to someone about questions about life, or ‘why’ questions? | X |  |  |  | X | X | X |  | Yes, as number 7 |
| 8. | Cultural background | X | Is there something that I should know about your cultural background or religion in order to provide you with proper care? |  | X |  |  |  |  |  |  | Yes, as number 8 |
| 9. | Financial needs related to care | X | Are you worried about money matters as a result of your condition? |  | X |  | X |  | X |  |  | Yes, as number 9 |
| 10. | Advanced care planning regarding the disease | X | Do you have any questions or concerns about your future with COPD? |  | X |  | X | X | X |  |  | Yes, as number 10 |
| 11. | Advanced care planning regarding future care | X  | Would you like to talk about the treatment and care you would like to receive if your condition continues to deteriorate? |  |  | X | X | X | X |  |  | Yes, as number 11 |
| 12.  | Informal caregiver needs: support | X | We have often found that informal caregivers would like to receive more help from others. Does that also apply to you? | X | X | X | X | X | X |  | X | Yes, as number 14 |
| 13 | Informal caregiver needs: Information | X | (Question for patient, if informal caregiver is not present). Would your informal caregiver like to receive a further explanation about COPD or about the treatment? |  |  |  |  |  |  |  | X |  |
| (Question for informal caregiver, if present). Would you like to receive a further explanation about COPD or about the treatment? |  |  |  |  |  |  |  | X |  |
| 14. | Lifestyle concerns  |  | Many people with COPD feel that there is little space to talk openly about their lifestyle choices (e.g., exercise, diet, or smoking). Does this also apply to you? | X | X |  | X |  | X |  |  | Yes, as number 12 |
| 15. | Availability and accessibility of care |  | Do you have a point of contact when you are not well? | X | X | X |  |  | X |  |  |  |
| 16. | Self-Management needs  |  | Many people with COPD feel unable to control the disease. Does this also apply to you? | X |  | X |  | X | X |  |  |  |
| 17. | Maintaining hobbies  |  | Does COPD affect your hobbies? |  |  |  |  |  |  |  |  |  |
| 18. | Maintaining optimism  |  | Do you find it difficult to stay positive due to COPD? |  |  |  | X | X | X |  |  |  |
| 19. | Social burden |  | Does COPD affect your social life more than you want? |  | X | X | X | X | X | X |  | Yes, included in number 6 |
| 20. | Intimacy needs |  | Some people with COPD experience changes in their intimacy. Does this also apply to you? | X | X |  | X |  | X |  | X | Yes, as number 13 |

**Figure A**
Final version of I-HARP for COPD in English (without Dutch recommendations, part 3 while these refer to national sources, organizations, instruments, guidelines etc.)



