APPENDIX: Dignity-conserving care – outcomes studied in research

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| **Cluster theme** | **Themes related to Illness-Related Concerns** | |
| **Theme of studied outcomes** | **Performance, symptoms and emotional concerns** | |
|  | **Operationalization of outcomes** | **References** |
| **Performance status**  **The Palliative Performance Scale**  **The Palliative Performance Scale–version 2 (PPSv2)**  **Symptoms**  **The Edmonton Symptom Assessment System (ESAS)**  **Symptoms and concerns**  **The Structured Interview for Symptoms and Concerns (SISC)**  **Psychophysiological wellbeing**  **Heart rate variability (HRV)**  **Distress**  **The Distress Thermometer**  **Affective states**  **The Positive and Negative Affect Schedule (PANAS)**  **Psychological wellbeing**  **The Life Closure Scale (LCS) consisting of 20 items**  **Psychological distress**  **The Geriatric Depression Scale**  **The Distress Thermometer**  **The Hospital Anxiety and Depression Scale (HADS)**  **Patient Health Questionnaire-9**  **The Structured Interview for Symptoms and Concerns (SISC)**  **The McGill Quality of Life questionnaire**  **Depression**  **The Hospital Anxiety and Depression Scale (HADS)**  **The 15-item Geriatric Depression Scale**  **The second edition of the 21-item Beck Depression Inventory**  **The Zung Self-Rating Depression Scale**  **Anxiety**  **The Hospital Anxiety and Depression Scale (HADS)** | **(Chochinov et al., 2011) Study 5 (S5)**  **(Houmann et al., 2014) S10**  **(Chochinov et al., 2011; Vergo et al., 2014) S5, S19**  **(Chochinov et al., 2011; Houmann et al., 2014) S5, S10**  **(Ho et al., 2017) S23**  **(Vergo et al., 2014) S19**  **(Montross-Thomas et al., 2015) S15**  **(Montross-Thomas et al., 2015) S15**  **(Hall, Chochinov et al., 2009) S6**  **(Hall, Edmonds et al., 2009) S7**  **(Hall, Goddard, Opio, Speck, Martin et al., 2011) S9**  **(Ho et al., 2017) S23**  **(Chochinov et al., 2011) S5**  **(Ho et al., 2016) S22**  **(Chochinov et al., 2011 S5; Hall, Goddard, Opio, Speck, Martin et al., 2011 S9; Houmann et al., 2014 S10; Julião et al., 2013 S12; Julião et al., 2014 S13; Montross - Thomas et al., 2015 S15; Rudilla et al., 2016 S17)**  **(Hall, Goddard, Opio, Speck & Higginson, 2011) S8**  **(Johns, 2013) S11**  **(Passik et al., 2004) S16**  **(Chochinov et al., 2011 S5; Hall, Goddard, Opio, Speck, Martin et al., 2011 S9; Houmann et al., 2014 S10; Julião et al., 2013 S12; Julião et al., 2014 S13, Montross - Thomas et al., 2015 S15; Rudilla et al., 2016 S17)** |

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| **Theme of studied outcomes** | **End of life and existential aspects** | |
|  | **Operationalization of outcomes** | **References** |
| **End of life psychological experiences**  **Through the Demoralization Syndrome (DS) criteria, Desire for Death scale and Sense of Dignity (Patient Dignity Inventory)**  **Palliative care needs**  **The Palliative Care Outcome Scale (POS)**  **Goals of care and treatment preferences at end of life**  **The Hypothetical Advanced Care Planning Scenario (H-CAP-S)**  **Sense of life closure**  **The Life Closure Scale (LCS)**  **The Herth Hope Index (HHI)**  **Existential wellbeing**  **The Functional Assessment of Chronic Illness Therapy-8-item Spiritual Well-Being Scale (FACIT-Sp.)**  **Existential distress**  **The Structured Interview for Symptoms and Concerns (SISC)**  **On five items (anxiety, sense of suffering, desire for death, lack of wellbeing, perceived loss of dignity) - lower scores indicating less existential distress**  **Purposelessness**  **The Purposelessness, Understimulation and Boredom (PUB) scale**  **Will to live**  **A will-to-live visual analogue scale included in the Edmonton Symptom Assessment System (ESAS)**  **Desire for death**  **The Desire for Death Rating Scale (DDRS)** | **(Julião et al., 2017) S14**  **(Hall, Edmonds et al., 2009;** **Hall, Goddard, Opio, Speck, Martin et al., 2011) S7, S9**  **(Vergo et al., 2014)** **S19**  **(Montross-Thomas et al., 2015) S15**  **(Hall, Goddard, Opio, Speck, Martin et al., 2011) S9**  **(Bernat et al., 2015) S3**  **(Chochinov et al., 2011) S5**  **(Johns, 2013) S11**  **(Passik et al., 2004) S16**  **(Chochinov et al., 2005; Chochinov et al., 2011) S4, S5**  **(Julião et al., 2017) S14** |
| **Cluster theme** | **Themes related to the Dignity-Conserving Repertoire** | |
| **Themes of studied outcomes** | **Essential life values** | |
|  | **Operationalization of outcomes** | **References** |
| **Hope**  **The Herth Hope Index (HHI)**  **Hopefulness**  **The Herth Hope Index (HHI)**  **Meaning in life**  **The Life Evaluation Questionnaire (the 5-item Appreciation of Life subscale, the 8-item Contentment subscale and the 8-item Social Integration subscale)**  **A modified Cancer Coherence scale**  **Spirituality**  **The Grupo de Espiritualidad (GES) questionnaire**  **The Dignity Impact Scale (DIS)**  **Spiritual wellbeing**  **The Functional Assessment of Chronic Illness Therapy-12-item Spiritual Well-Being Scale (FACIT-sp.)** | **(Bentley et al., 2014; Montross-Thomas et al., 2015) S2, S15**  **(Aoun et al., 2015 S1; Hall, Goddard, Opio, Speck, Martin et al., 2011 S9; Hall, Chochinov et al., 2009 S6; Hall, Edmonds et al., 2009 S7; Hall, Goddard, Opio, Speck & Higginson, 2011 S8; Ho et al., 2017 S23)**  **(Montross-Thomas et al., 2015) S15**  **(Ho et al., 2017) S23**  **(Rudilla et al., 2016) S17**  **(Scarton et al., 2018) S18**  **(Aoun et al., 2015 S1; Bentley et al., 2014 S2; Chochinov et al., 2011 S5;** **Ho et al., 2017 S23)** |
| **Theme of studied outcomes** | **Aspects of personal strength and coping** | |
|  | **Operationalization of outcomes** | **References** |
| **Self-efficacy**  **The General Self-Efficacy Scale (GSE)**  **Resilience**  **The Connor-Davidson Resilience Scale (CD-RISC)**  **The Brief Resilient Coping Scale (BRCS)**  **Empowerment**  **The Empowerment Scale**  **Post-traumatic** **growth**  **The Posttraumatic Growth Inventory (PTGI)**  **Psychological adaptation**  **The Life Closure Scale (LCS)**  **Death acceptance**  **The Terminal Illness Acknowledgement (TIA) questionnaire** | **(Montross-Thomas et al., 2015) S15**  **(Montross-Thomas et al., 2015) S15**  **(Rudilla et al., 2016) S17**  **(Roos et al., 2016) S26**  **(Da Rocha Rodrigues et al., 2016) S21**  **(Montross-Thomas et al., 2015) S15**  **(Vergo et al., 2014) S19** |
| **Cluster theme** | **Themes related to the Social Dignity Inventory** | |
| **Theme of studied outcomes** | **Aspects of care tenor and social support** | |
|  | **Operationalization of outcomes** | **References** |
| **Person-centred care climate**  **The Person-centered Climate Questionnaire-patient (PCQ-P) measuring three subscales: a climate of safety, a climate of everydayness and a climate of hospitality**  **Empathy**  **The Consultation and Relational Empathy (CARE) measure**  **The Empathy questionnaire (for health care professionals)**  **Social support**  **The Duke-UNC-11 Functional Social Support Questionnaire**  **A modified version of the Inventory of Social Support** | **(Johnston, Gaffney et al., 2015 S24; Johnston, Pringle et al., 2015 S25; Roos et al., 2016 S26)**  **(Johnston, Pringle et al., 2015) S25**  **(Chochinov et al., 2015) S20**  **(Rudilla et al., 2016) S1**  **(Ho et al., 2017) S23** |
| **Cluster theme** | **Themes regarding Overarching Dignity Issues** | |
| **Theme of studied outcomes** | **Aspects of dignity and gratitude** | |
|  | **Operationalization of outcomes** | **References** |
| **Sense of dignity**  **The Patient Dignity Inventory (PDI)**  **Dignity-related distress**  **The Patient Dignity Inventory (PDI)**  **Gratitude**  **The Gratitude Questionnaire Six-Item Form (GQ-6) measuring experience of gratitude, forgiveness and spiritual transcendence**  **Appreciation of life**  **The 5-item Appreciation of Life subscale as one subscale in the Life Evaluation Questionnaire** | **(Julião et al., 2017;** **Ho et al., 2017) S14 ,S23**  **(Aoun et al., 2015 S1; Bentley et al., 2014 S2;** **Bernat et al., 2015 S3; Chochinov et al., 2011 S5; Hall, Chochinov et al., 2009 S6; Hall, Edmonds et al., 2009 S7; Hall, Goddard, Opio, Speck & Higginson, 2011 S8; Hall, Goddard, Opio, Speck, Martin et al., 2011 S9; Houmann et al., 2014 S10; Rudilla et al., 2016 S17;Da Rocha Rodrigues et al., 2016 S21)**  **(Montross-Thomas et al., 2015) S15**  **(Montross-Thomas et al., 2015) S15** |
| **Theme of studied outcomes** | **Aspects of quality of life** | |
|  | **Operationalization of outcomes** | **References** |
| **Quality of life**  **The Amyotrophic Lateral Sclerosis Assessment Questionnaire-5 (ALS-FRS)**  **A two-item Quality of Life Scale with ratings of quality of life and satisfaction with quality of life**  **The Euro QoL Five Dimensions (EQ-5D)**  **Items from the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life C30 Questionnaire (EORTC–QLQ–C30)**  **The McGill Quality of Life questionnaire**  **The World Health Organization (WHO) Quality of Life Scale-8**  **Satisfaction with life**  **The Satisfaction with Life Scale (SWLS)**  **The Life Satisfaction Questionnaire (LSQ)**  **Health-related quality of life**  **The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life C15 Questionnaire Palliative care (QLQ-C15-PAL)**  **Functional Assessment of Chronic Illness Therapy-Palliative Care version 4 (FACIT-PAL)**  **Nursing home quality of life**  **The Nursing Facilities Quality of Life scale** | **(Aoun et al., 2015) S1**  **(Chochinov et al., 2005 S4; Chochinov et al., 2011 S5; Hall, Chochinov et al., 2009 S6; Hall, Edmonds et al., 2009 S7; Hall, Goddard, Opio, Speck & Higginson, 2011 S8; Hall, Goddard, Opio, Speck, Martin et al., 2011 S9; Vergo et al., 2014 S19)**  **(Hall, Chochinov et al., 2009 S6; Hall, Edmonds et al., 2009 S7; Hall, Goddard, Opio, Speck & Higginson, 2011 S8; Hall, Goddard, Opio, Speck, Martin et al., 2011 S9)**  **(Rudilla et al., 2016) S17**  **(Ho et al., 2016) S22**  **(Ho et al., 2017) S23**  **(Da Rocha Rodrigues et al., 2016) S21**  **(Roos et al., 2016) S26**  **(Houmann et al., 2014) S10**  **(Johns, 2013) S11**  **(Ho et al., 2016) S22** |