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** |