

Appendix 1 Manifoldness of facets and triggers of existential suffering

Patients, relatives and health care professionals describe the experience of existential suffering in a wide variety of terms and a range of psychological symptoms, which is reflected in the international medical literature. These range from various losses, helplessness, being a burden to others, fear of death and dying, to loss of meaning and purpose in life, which results in hopelessness and despair (22,41,78,147,160-162).

Bozzaro describes the four burdensome phenomena of suffering (16):

- (I) Slave to your own body and its caprices; feeling alienated from one's own body or imprisoned in it
- (II) No hope of improvement in sight
- (III) No place in the world; e.g., loss of role, perceived uselessness or fear of being a burden to others
- (IV) No answer to the question of meaning - no plausible explanations

From an existential analytic perspective, Yalom described the four existential domains of "death, freedom, isolation, meaninglessness" (163). Based on this, Kissane published 2012 a typology of existential distress, including the following 8 major forms: death anxiety, loss and change, freedom with choice or loss of control, dignity of the self, fundamental aloneness, altered quality of relationships, meaning and mystery (52).

In a further development of the short 6 item DS-6 (Demoralisation Scale) and the ESAS (Edmonton Symptom Assessment Scale), the PeSAS (Psycho-existential Symptom Assessment Scale) was created, which was published in 2022 by Kissane *et al.* The 10 items are: anxiety, discouragement, trapped by illness, hopelessness, pointlessness, loss of control, loss of roles, depression, wish to die and confusion (15).

Exemplary, quite similar to the landscape of distress in the terminally ill published by Chochinov *et al.* (164), the following table describes the triggers for existential suffering:

Physical symptoms (pain, nausea)	51.47%
Feeling of being at the mercy of circumstances / loss of control (in everyday life, in relation to illness/therapy ...)	48.53%
Powerlessness, helplessness	41.18%
Fear of suffering in the dying process	38.82%
Being a burden to others	35.88%
Dependence, being reliant	33.24%
Unfinished business/life tasks	25.59%
Worthlessness, loss of role	23.53%
Hopelessness	19.12%
Confrontation with finitude	16.76%
Social problems	16.18%
Fear of death	16.18%
Loss of sense of dignity	15.00%
Wish to die, loss of will to live	13.82%
Sense of meaninglessness	12.35%
Loneliness, isolation	12.35%
Decrease in mental abilities (thinking, concentration ...)	9.71%
Altered body image	9.41%
Loss of previous interests or enjoyment for activities	8.24%
Spiritual distress	7.94%
Grief	5.59%
Pronounced sense of guilt	5.00%
Shame	1.76%

Triggers for existential suffering, perceived by professional palliative caregivers (14)
[Percentage of 326 surveyed carers in Austrian interprofessional teams]

References

160. van Deijck RHPD, Hasselaar JGJ, Krijnsen PJC, et al. The Practice of Continuous Palliative Sedation in Long-Term Care for Frail Patients with Existential Suffering. *J Palliat Care* 2015;31:141-9.
161. Breitbart W, Gibson C, Poppito SR, et al. Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality. *Can J Psychiatry* 2004;49:366-72.
162. Henoeh I, Danielson E. Existential concerns among patients with cancer and interventions to meet them: an integrative literature review: Existential concerns among patients with cancer. *Psychooncology* 2009;18:225-36.
163. Yalom ID. *Existenzielle Psychotherapie: mit einem Vorwort des Autors '25 Jahre Existenzielle Psychotherapie' und einem Interview mit Irvin Yalom von Ulfried Geuter 'Sich berühren lassen'*. 5., korr. Aufl. Bergisch Gladbach: EHP; 2010. 610 p.
164. Chochinov HM, Hassard T, McClement S, et al. The Landscape of Distress in the Terminally Ill. *J Pain Symptom Manage* 2009;38:641-9.

Appendix 2 End-of-life concerns, triggers for the urge for an exit strategy (PST, WTD, WTHD), exemplary as mentioned in the Oregon Death with Dignity Act - 2022 Data Summary; N=278

Less able to engage in activities making life enjoyable	88.8%
Losing autonomy	86.3%
Loss of dignity	61.9%
Burden on family, friends/caregivers	46.4%
Losing control of bodily functions	44.6%
Inadequate pain control, or concern about it	31.3%
Financial implications of treatment	6.1%

Oregon Health Authority. Oregon Death with Dignity Act - 2022 Data Summary [Internet]. Public Health Division; 2022 [cited 2023 Apr 5]. Available from: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year25.pdf>

Table S1 Search strategy summary (PubMed search 12.4.2023)

No.	Topic	Search	Total count	Reviews, systemic reviews
#1	Suffering	((suffering) OR (distress)) OR (despair)	1,642,550	
#2	Existential	(((((existential) OR (spiritual)) OR (psychoexistential)) OR (demoralisation)) OR (hopelessness)) OR (dignity)) OR (meaninglessness)	522,107	
#3	Unbearable	(((((unbearable) OR (intractable)) OR (refractory)) OR (unremitting)) OR (intolerable)) OR (unendurable)	262,623	
#4	Palliative	((((palliative) OR (terminally))) OR (end of life)) OR (hospice)	1,837,717	
#5	Guidelines + sedation	(((((guideline[Title]) OR (policy[Title])) OR (framework[Title])) OR (recommendation[Title])) OR (protocol[Title])) OR (guidelines as topic[MeSH Terms])) OR (policy[MeSH Terms])) AND (sedation)	1,739	401
#1 AND #2		existential suffering	41,763	
#1 AND #2 AND #3		unbearable existential suffering	924	187
#1 AND #2 AND #3 AND #4		unbearable existential suffering AND palliative	312	64
#1 AND #2 AND #3 AND #4 AND #5		unbearable existential suffering AND palliative sedation AND guidelines	5	3
#4 AND sedation		palliative sedation	4,198	723
#4 AND #5		palliative sadation AND guidelines	223	51
#1 AND #2 AND #4		existential suffering AND palliative	6,592	1100
#1 AND #2 AND #4 AND (sedation)		existential suffering AND palliative sedation	176	36
#1 AND #2 AND #4 AND #5		existential suffering AND palliative sedation AND guidelines	10	4
#6	Good dying/ death	((quality of death and dying[title]) OR ((good death[title]) OR ((good dying[title]))))	453	36
#6 AND (sedation)			6	1
#6 AND (Holland)			14	
#6 AND (Belgium)			3	
#6 AND (assisted dying)			22	1
#6 AND (euthanasia)			97	9