Death and Dying

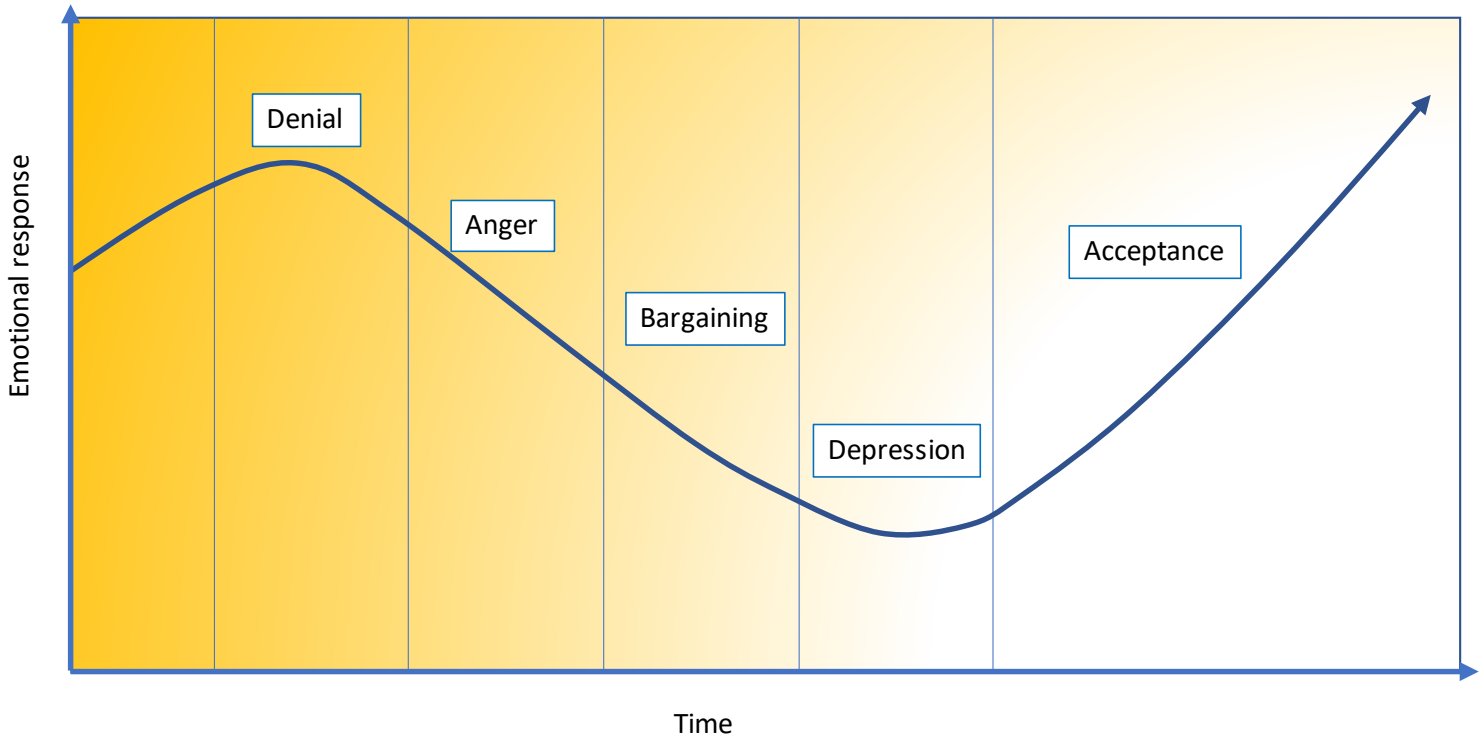
Kübler-Ross Model for Terminal Illness and Grief

Advanced Care Planning

Hospice

Grief and Complicated Grief

Kübler-Ross Model for Terminal Illness and Grief



Kübler-Ross Model for Terminal Illness and Grief

- Based on previous theoretical notions of Bowlby and Parkes (1970)
- Originally focused on dying but later applied to grief (Kübler-Ross & Kessler, 2005)
- Often represented incorrectly in popular media and in textbooks (Avis et al., 2021; Corr, 2020)
- Did not necessary state that all stages would be experienced by everyone, for example

Avis, K. A., Stroebe, M., & Schut, H. (2021). Stages of grief portrayed on the internet: A systematic analysis and critical appraisal. *Frontiers in psychology*, *12*, 772696.
Corr, C. A. (2020). Elisabeth Kübler-Ross and the "five stages" model in a sampling of recent American textbooks. *OMEGA-Journal of Death and Dying*, *82*(2), 294-322.

Kübler-Ross Model for Terminal Illness and Grief

Critiques

- Not supported by evidence (e.g., Maciejewski, Zhang, Block, & Prigerson, 2007)
- "The fact is, no study has ever established that stages of grief actually exist, and what are defined as such can't be called stages." (Avis et al., p. 2)
- Unlikely that these stages have to be experienced for proper adjustment (i.e., when grieving) (Wortman & Silver, 1989)
- No reason the "stages" would have to be experienced sequentially in that order (Corr, 2020)
- May lead some to believe they are grieving "incorrectly" (Avis et al., 2021)

Avis, K. A., Stroebe, M., & Schut, H. (2021). Stages of grief portrayed on the internet: A systematic analysis and critical appraisal. *Frontiers in psychology*, *12*, 772696.
Corr, C. A. (2020). Elisabeth Kübler-Ross and the "five stages" model in a sampling of recent American textbooks. *OMEGA-Journal of Death and Dying*, *82*(2), 294-322.

Kübler-Ross Model for Terminal Illness and Grief

Avis et al. (2021) study of whether discussions note limitations of the model on internet sites

TABLE 3 | Frequencies and percentages of warnings, limitations, and criticisms of five stages model.

		N	%
Warning			
	Warning: Non-rigidity		
	Non-linearity	26	59.1
	Not all 5 stages	22	50
	Varied intensity of stages	3	6.8
	No timetable/set time	12	27.3
	More than 5 stages	4	9.1
	Concurrency of stages	4	9.1
	Recurrence of stages	10	22.7
	Warning: Non-existence		
	Non-prescriptive	15	34.1
	Harmful	4	9.1
	Unhelpful	3	6.8
Limitation			
	Lack scientific research	4	9.1
Criticisms			
	Misapplied from terminal patients	4	9.1
	Other models superior	8	18.2
	Other metaphors superior	3	6.8
	Misrepresentation of grief	10	22.7

The frequencies and percentages are based on the sub-sample of websites (n = 44) that referenced the five stages model.

Avis, K. A., Stroebe, M., & Schut, H. (2021). Stages of grief portrayed on the internet: A systematic analysis and critical appraisal. *Frontiers in psychology*, *12*, 772696.

Kübler-Ross Model for Terminal Illness and Grief

Benefits

- Good that it brought attention to the dying process and grief
- Awareness of common responses is likely helpful
- Provides some validation that feelings such as denial or anger are normal and acceptable
- May be useful basis for discussing feelings with others
- Notion of acceptance gives hope that the grieving person (or dying person) will be able to come to terms with the death
- Concept of continuing bond with grieving – person lives on in your memory (Klass, Silverman, & Nickman, 1996)

Advanced Care Planning (ACP)

"Advance care planning involves discussing and preparing for future decisions about your medical care if you become seriously ill or unable to communicate your wishes. Having meaningful conversations with your loved ones is the most important part of advance care planning. Many people also choose to put their preferences in writing by completing legal documents called advance directives." - NIA

https://www.nia.nih.gov/health/advance-care-planning/advance-care-planning-advance-directives-health-care

Advanced Care Planning (ACP)

Legal

Living will – instructions to doctors about treatment if unable to make decisions yourself

Durable power of attorney for health care – designates a "proxy" or "surrogate" for making decisions if you cannot make them

https://www.nia.nih.gov/health/advance-care-planning/advance-care-planning-advance-directives-health-care

Advanced Care Planning (ACP)

Advance care planning decisions

Life Support Orders

Heartbeat
Restoring heartbeat by pushing on the chest, medication, or defibrillation (electric shocks)

Breathing
Bringing air into the lungs by a tube pushed into the windpipe connected to ventilator.

Digestion
Providing nutrition with a tube inserted into the stomach or by hand feeding.

Healthcare Proxy

Proxy
Someone to make treatment decisions if the patient is

MOLST
Medical orders for life-sustaining treatments to be acted on immediately, intended for nurse practitioner or physician assistant.

Advanced Care Planning (ACP)

Example of Instruction Grid for Specific Directives (Ditto & Hawkins, 2005)

	CPR	Ventilation	Dialysis	Surgery	Blood Transfusion	Antibiotics	Tube Feeding
Current Health							
Mild Stroke							
Moderate Stroke							
Severe Stroke							
Mild Dementia							
Moderate Dementia							
Severe Dementia							
Permanent Coma							
Pain Syndrome							

Figure 1. Instruction grid (Singer, 1993). For each combination of health state and treatment, the person completing the living will is told to imagine him- or herself in the indicated health state and write one of four choices about his or her desire to receive each treatment in that health state: *yes* (if he or she wants the particular treatment in that health state), *no* (if he or she does not want the particular treatment in that health state), *undecided* (if he or she is undecided about the particular treatment in that health state), or *trial* (if he or she wants a trial of the particular treatment in that health state). CPR = cardiopulmonary resuscitation. From "The University of Toronto Centre for Bioethics Living Will," by P. A. Singer, 1993, *Ontario Medical Review, 63,* p. 35. Copyright 1993 by P. A. Singer. Reprinted with permission of the author.

Ditto, P. H., & Hawkins, N. A. (2005). Advance directives and cancer decision making near the end of life. Health Psychology, 24(4S), S63.

Advanced Care Planning (ACP)

Palmer et al 2021 Study of Medicare Beneficiaries

Outpatient advance care planning (ACP) claims of fee-for-service Medicare beneficiaries, by patient characteristics, 2017

	Beneficiaries who had:			
Characteristics	(1) Any ACP claim	(2) ACP claim at annual wellness visit	(3) ACP claim apart from annual wellness visit	(4) Beneficiaries with an ACP claim who had ACP at annual wellness visit
Total	2.86%	1.54%	1.40%	54.03%
Age, years				
<65	1.37	0.68	0.73	49.92
65–74	2.57	1.62	1.04	62.84
75–84	3.59	1.99	1.71	55.37
85+	4.66	1.66	3.13	35.64
Race/ethnicity				
White	2.83	1.57	1.35	55.30
Black	2.84	1.36	1.57	47.85
Asian	4.00	2.00	2.16	50.02
Hispanic	3.09	1.50	1.71	48.64
Other and unknown	2.14	1.19	1.01	55.77
Sex				
Male	2.61	1.41	1.28	54.06
Female	3.06	1.65	1.51	54.01
Dual eligibility status				
In FFS Medicare, Medicaid eligible	2.80	1.15	1.73	41.25
In FFS Medicare only	2.87	1.64	1.33	56.93
Died within the calendar year				
Yes	7.16	0.52	6.72	7.26

Palmer, M. K., Jacobson, M., & Enguidanos, S. (2021). Advance Care Planning For Medicare Beneficiaries Increased Substantially, But Prevalence Remained Low: Study examines Medicare outpatient advance care planning claims and prevalence. *Health Affairs*, *40*(4), 613-621.

Advanced Care Planning (ACP)

"This research demonstrates that across a wide variety of decision contexts people show limited ability to predict their affective and behavioral reactions to future situations."

-(Ditto et al., 2005, p. 481)

Ditto, P. H., Hawkins, N. A., & Pizarro, D. A. (2005). Imagining the end of life: On the psychology of advance medical decision making. Motivation and Emotion, 29(4), 475-496.

Advanced Care Planning (ACP)

Ditto et al. 2006 Study

Prospective study of 88 individuals before hospitalization, during recovery, and then a few months afterward

Immediately following hospitalization, patients became less favorable toward life-sustaining treatments, especially for the most invasive interventions

People's preferences for end of life care depend on their current health state

Ditto, P. H., Jacobson, J. A., Smucker, W. D., Danks, J. H., & Fagerlin, A. (2006). Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision Making*, *26*(4), 313-322.

Advanced Care Planning (ACP)

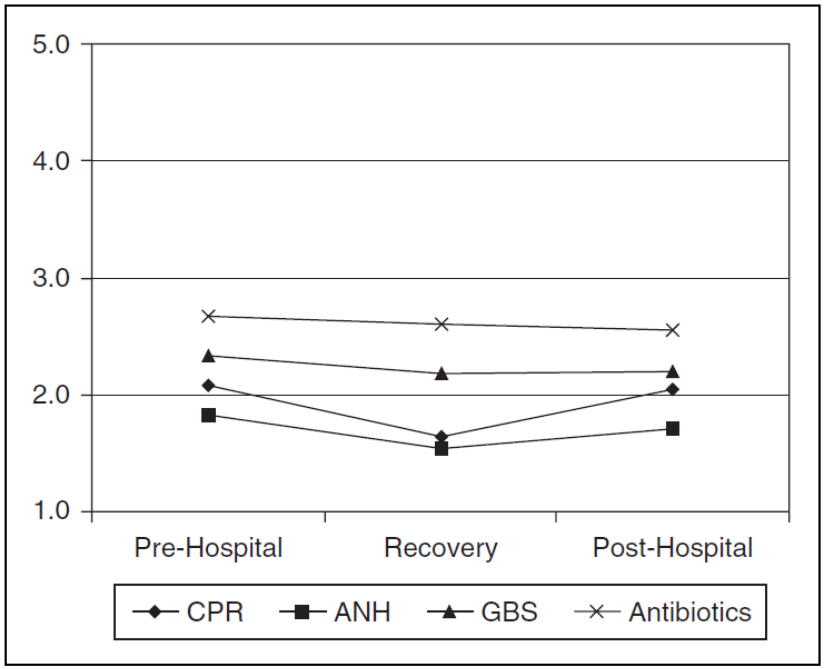


Figure 1 Mean treatment preferences at the prehospitalization, recovery, and posthospitalization interviews. CPR, cardiopulmonary resuscitation; ANH, artificial nutrition and hydration; GBS, gall bladder surgery.

Ditto, P. H., Jacobson, J. A., Smucker, W. D., Danks, J. H., & Fagerlin, A. (2006). Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision Making*, *26*(4), 313-322.

Advanced Care Planning (ACP)

Surrogates also unprepared (Bakke et al., 2022)

(1) lack of, but needing, surrogates' own preparation and guidance

(2) initiate ACP conversations,

(3) learn patient's values and preferences,

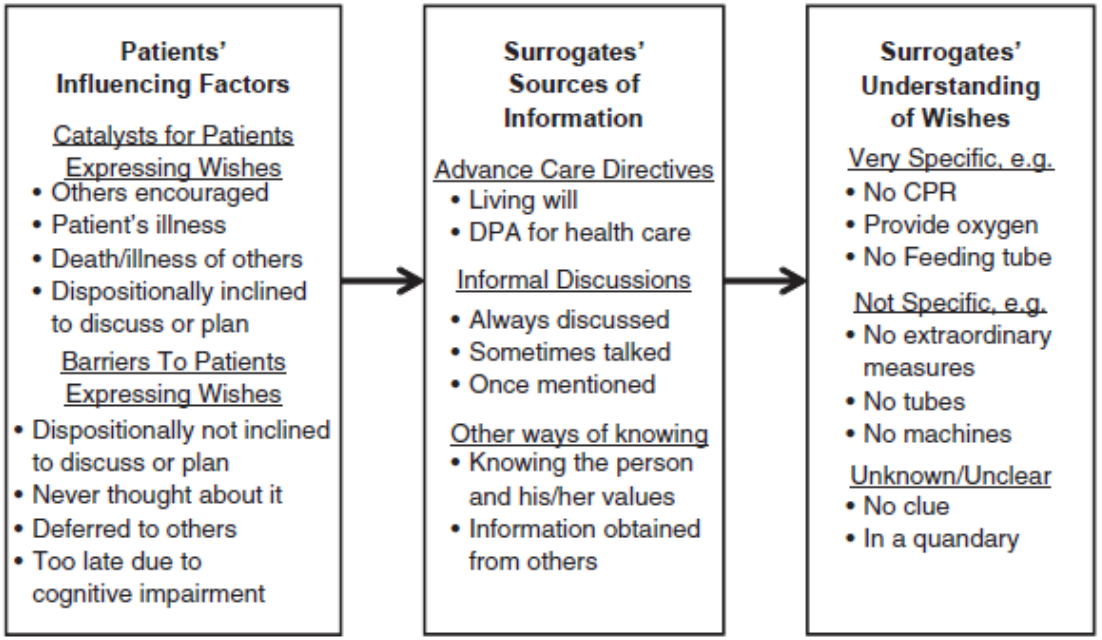
(4) communicate with clinicians and advocate for patients, and

(5) make informed surrogate decisions.

Bakke, B. M., Feuz, M. A., McMahan, R. D., Barnes, D. E., Li, B., Volow, A. M., ... & Sudore, R. L. (2022). Surrogate decision makers need better preparation for their role: advice from experienced surrogates. *Journal of Palliative Medicine*, *25*(6), 857-863.

Advanced Care Planning (ACP)

A Model of How Surrogate Decision Makers Develop an Understanding of Dementia Patients' End-of-Life Care Wishes



Note: DPA = durable power of attorney; CPR = cardiopulmonary resuscitation.

Black, B. S., Fogarty, L. A., Phillips, H., Finucane, T., Loreck, D. J., Baker, A., ... & Rabins, P. V. (2009). Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. Journal of aging and health, 21(4), 627-650.

Advanced Care Planning (ACP)

Table 2
Surrogates' Reports of Patients' Most Common Wish to Not Be Kept Alive by "Machines" or "Extraordinary Measures"

Not on a machine just to stay alive
No life suspension
No keeping alive with machines
Not prolong this life
If we ever got terminal, don't hook us up to anything
We don't want life extended by artificial means
No advance life support
"I wouldn't want to be kept alive by a machine"
Not on any type of machinery to keep her alive; "I don't want to be kept alive artificially"
She wouldn't want to be hooked up to any system to keep her
Absolutely no extra activities to keep him alive
No life support
If it's her time she wants to go. "Don't keep me here. Don't hook me up."
Didn't want to be on no support thing, like something to keep her living
Didn't want to be held for 5 years on artificial nourishment

Black, B. S., Fogarty, L. A., Phillips, H., Finucane, T., Loreck, D. J., Baker, A., ... & Rabins, P. V. (2009). Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. Journal of aging and health, 21(4), 627-650.

Advanced Care Planning (ACP)

Sharman et al. (2008) Study of Surrogates

Asked 12 months apart:

"If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?"

1=definitely would not want,
2 = probably would not want,
3=unsure,
4 =probably would want
5 =definitely would want

Sharman, S. J., Garry, M., Jacobson, J. A., Loftus, E. F., & Ditto, P. H. (2008). False memories for end-of-life decisions. Health Psychology, 27(2), 291.

Advanced Care Planning (ACP)

Sharman et al. (2008) Study of Surrogates

Table 1
Hypothetical Scenarios and Treatments

Scenario	
1	Participants' current health state
2	Alzheimer's disease
3	Emphysema
4a	Stroke-induced coma with no chance of recovery
4b	Stroke-induced coma with a very slight chance of recovery
5a	Stroke-induced partial paralysis with no chance of recovery
5b	Stroke-induced partial paralysis with a very slight chance of recovery
6a	Colon cancer that has spread to the liver requiring no pain relief
6b	Colon cancer that has spread to the liver requiring pain relief
Treatment	
1	Antibiotics
2	Cardiopulmonary resuscitation (CPR)
3	Gall bladder surgery
4	Artificial nutrition and hydration (tube feeding)

Note. For their current health state, participants did not rate the extent to which they would want to receive tube feeding.

Sharman, S. J., Garry, M., Jacobson, J. A., Loftus, E. F., & Ditto, P. H. (2008). False memories for end-of-life decisions. Health Psychology, 27(2), 291.

Advanced Care Planning (ACP)

Sharman et al. (2008) Study of Surrogates

23% of decisions changed over the 12-month period

- From not wanting treatment to wanting treatment (62%)
- From wanting treatment to not wanting treatment (38%)

Sharman, S. J., Garry, M., Jacobson, J. A., Loftus, E. F., & Ditto, P. H. (2008). False memories for end-of-life decisions. Health Psychology, 27(2), 291.

Advanced Care Planning (ACP)

Sharman et al. (2008) Study of Surrogates

"Across all scenarios, 86% of the time surrogates incorrectly thought that their target's decisions had stayed the same."

Sharman, S. J., Garry, M., Jacobson, J. A., Loftus, E. F., & Ditto, P. H. (2008). False memories for end-of-life decisions. Health Psychology, 27(2), 291.

Hospice

PBS Hospice video

https://www.pbs.org/video/living-fully-your-partners-in-hospice/ 26 min

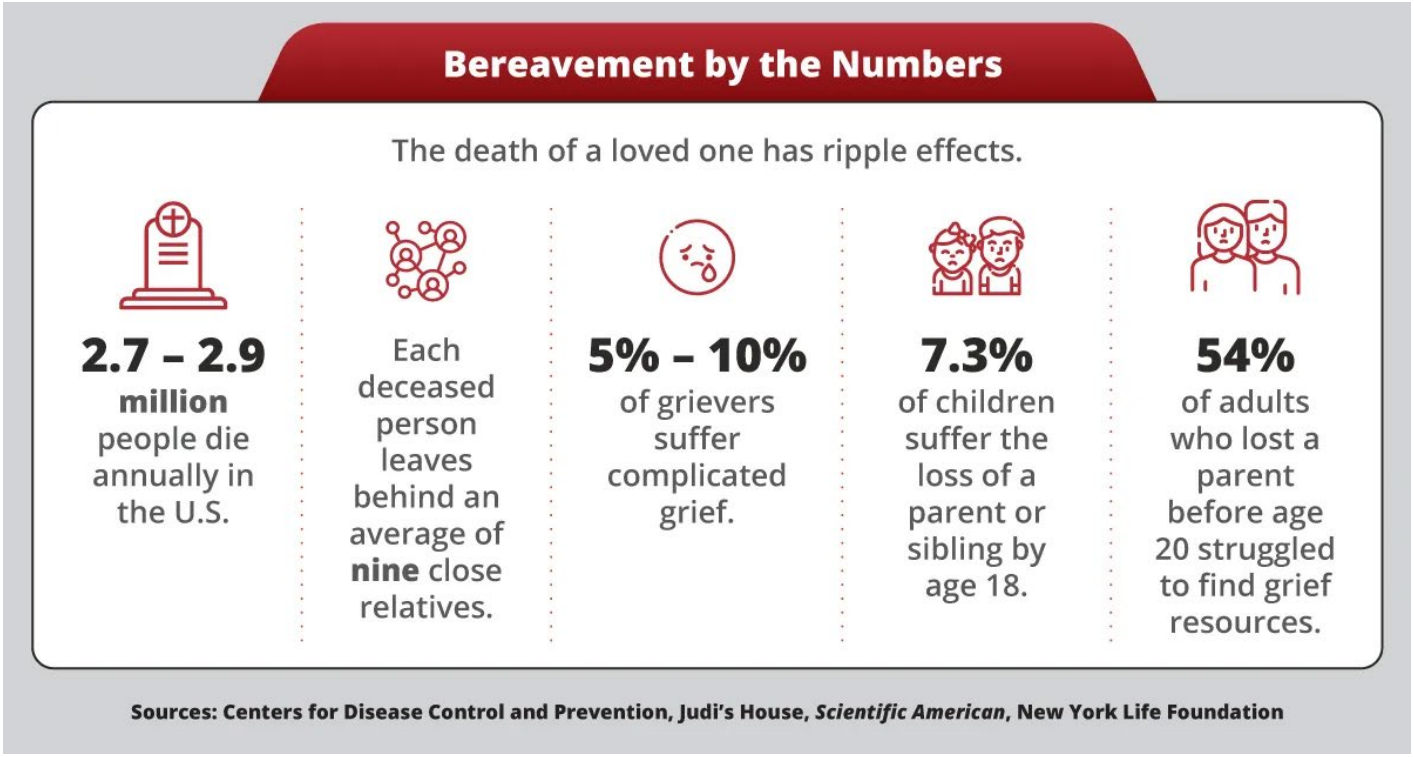
Grief and Complicated Grief

Grief is a normal process (Parkes, 2002)

But some individuals may have difficulty recovering, referred to as *unresolved* or *complicated* grief (Lazare, 1979; Wolfert, 1991)

Persistent or pervasive, clinically significant impairment, exceeds cultural expectations, persistent preoccupation, difficulty adapting, social withdrawl (Shear, 2015)

Grief and Complicated Grief



https://online.maryville.edu/blog/grief-counseling/

Grief and Complicated Grief

Table 2
Factor loadings for Inventory of Complicated Grief items

	Items
1.	I feel the urge to cry when I think about the person who died
2.	I find myself thinking about the person who died
3.	I think about this person so much that it's hard for me to do the things I normally do
4.	Memories of the person who died upset me
5.	I feel I cannot accept the death of the person who died
6.	I have feelings that it is unfair this person died
7.	I feel myself longing for the person who died
8.	I feel drawn to places and things associated with the person who died
9.	I can't help feeling angry about his/her death
10.	I feel disbelief over what happened
11.	I feel stunned or dazed over what happened
12.	Ever since he/she died, it is hard for me to trust people
13.	Ever since he/she died, I feel as if I have lost the ability to care about other people or I feel distant from people I care about
14.	I feel lonely a great deal of the time ever since he/she died
15.	I have pain in the same area of my body or have some of the same symptoms as the person who died
16.	I go out of my way to avoid reminders of the person who died
17.	I feel that life is empty without the person who died
18.	I hear the voice of the person who died speak to me
19.	I see the person who died stand before me
20.	I feel that it is unfair that I should live when this person died
21.	I feel bitter over this person's death
22.	I feel envious of others who have not lost someone close

Prigerson, H. G., Maciejewski, P. K., Reynolds III, C. F., Bierhals, A. J., Newsom, J. T., Fasiczka, A., ... & Miller, M. (1995). Inventory of complicated grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*, *59*(1-2), 65-79.

Grief and Complicated Grief

Risk factors for complicated grief (Burr et al., 2024)

Table 2
Adjusted predictors of PGS.

Predictor	K	N	I^2	T^2	ESr	95%CI	*p*	95%PI
Pre-loss grief symptoms	5	2585	0.88	0.03	0.39	0.24–0.53	**<0.001**	−0.21-0.78
Pre-loss depressive symptoms	6	2731	0.90	0.04	0.30	0.13–0.44	**<0.001**	−0.28-0.72
Death of a child	17	8555	0.94	0.04	0.26	0.17–0.35	**<0.001**	−0.17-0.61
Death of a partner	20	12,640	0.92	0.02	0.19	0.13–0.25	**<0.001**	−0.11-0.46
Attachment anxiety	8	2698	0.73	0.01	0.17	0.09–0.25	**<0.001**	−0.09-0.41
Income	6	4954	0.47	0.00	−0.12	−0.17- -0.07	**<0.001**	−0.23- -0.01
Violent/unnatural death	19	8354	0.61	0.00	0.12	0.08–0.16	**<0.001**	0.04–0.20
Educational level	25	13,544	0.93	0.03	−0.11	−0.18- -0.04	**0.001**	−0.44-0.25
Gender of bereaved (woman)	33	19,242	0.90	0.02	0.09	0.04–0.14	**<0.001**	−0.20-0.37
Unexpected death	7	1513	0.0	0.0	0.09	0.04–0.14	**0.001**	0.02–0.16
Religiosity	6	4178	89.2	0.01	0.09	−0.01-0.19	0.078	−0.22-0.38
Marital status (being single)	3	1999	0.49	0.0	0.08	0.01–0.14	**0.020**	−0.30-0.44
Neuroticism	3	463	0.0	0.0	−0.07	−0.16-0.03	0.157	−0.62-0.52
Age of deceased	10	4112	0.97	0.1	−0.13	−0.32-0.07	0.214	−0.72-0.56
Number of losses	9	7897	0.81	0.01	0.06	0.01–0.12	**0.030**	−0.19-0.30
Race (white)	5	2752	0.96	0.05	−0.06	−0.26-0.14	0.549	−0.69-0.62
Age of bereaved	36	20,107	0.89	0.02	0.02	−0.03-0.06	0.510	−0.26-0.30
Caregiver burden	3	2323	0.0	0.0	−0.02	−0.06-0.02	0.285	−0.27-0.23
Attachment avoidance	8	2984	0.95	0.05	0.00	−0.17-0.17	0.984	−0.53-0.53

Notes: Predictor: Sorted according to magnitude (ESr) of association; K = Number of independent samples analyzed; N = total number of participants in the analysis; I^2 = heterogeneity statistic, i.e., the percent of the variance attributable to systematic (non-random) between-study differences in the effect size; T^2 = Tau squared, i.e., the estimated variance of the true effect size; ESr = effect size correlation; 95%CI = 95% confidence interval of ESR; *p* = *p*-value (two-tailed); 95%PI = 95% prediction interval, i.e., the interval in which 95% of future observations from the same family of studies will fall.

Buur, C., Zachariae, R., Komischke-Konnerup, K. B., Marello, M. M., Schierff, L. H., & O'Connor, M. (2024). Risk factors for prolonged grief symptoms: A systematic review and meta-analysis. *Clinical Psychology Review*, *107*, 102375.

Grief and Complicated Grief

Treatment

https://online.maryville.edu/blog/grief-counseling/

Doering, B. K., & Eisma, M. C. (2016). Treatment for complicated grief: state of the science and ways forward. *Current Opinion in Psychiatry*, *29*(5), 286-291.

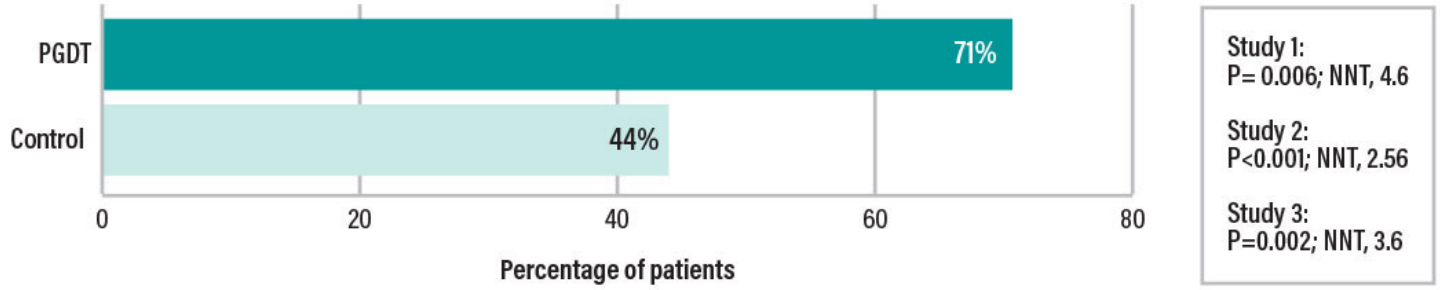
Grief and Complicated Grief

M. Katherine Shear PGDT Efficacy Studies

Using interpersonal psychotherapy or citalopram

Figure 2: Overall PGDT Results From Three Clinical Trials

Prolonged grief disorder treatment (PGDT) outperforms interpersonal psychotherapy for depression and citalopram for depression.



Source: Holly G. Prigerson, Ph.D., et al., *JAMA Psychiatry,* February 2, 2022.

Reynolds III, C. F., Prigerson, H. G., & Shear, M. K. (2023). Special Report: Prolonged Grief Disorder—What You Need to Know. https://psychiatryonline.org/doi/full/10.1176/appi.pn.2023.12.12.28

Iglewicz, A., Shear, M. K., Reynolds III, C. F., Simon, N., Lebowitz, B., & Zisook, S. (2020). Complicated grief therapy for clinicians: An evidence-based protocol for mental health practice. Depression and anxiety, 37(1), 90-98.