# Prolonged Grief Disorder

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## Women bear the burden of bereavement

#### + Widowhood rate

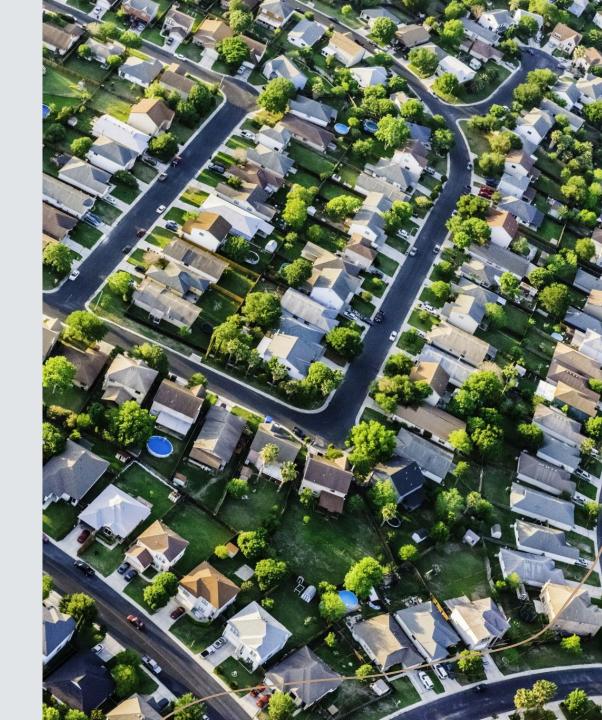
+ By age 65, nearly 40% of women, but 13% of men in America have been widowed (West, 2014).

#### + Caregiving

- + Women are more likely than men to provide caregiving to others, especially adult daughters/in-law (Pinquart and Sorenson 2006).
- + Poor physical and mental health during caregiving predicts prolonged grief disorder following loss (Lenger et al., 2020; Miller et al., 2020).

# Bereavement is a health disparity

- + BIPOC Americans are significantly disadvantaged by differential mortality rates—and thus, greater risk of bereavement.
  - + Too many, too soon.
- + The life course trauma of multiple family member deaths uniquely contributes to cardiometabolic risk of Black Americans (Donnelly, Cha, Umberson, 2022; Lewis et al., 2021).
- + Intersectionality: Race-ethnicity and gender intersect to shape socioeconomic conditions and life outcomes (Greenman & Xie, 2008).



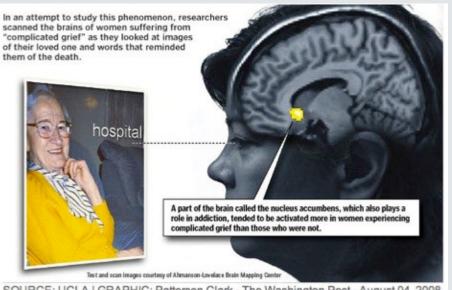
## Prolonged grief disorder (PGD)

- Included in WHO ICD-11 (2019) and DSM-5-TR (2022) (Prigerson, Shear, Reynolds, 2022).
  - + Characterized by persistent intense grief that interferes with functioning, exceeding expectations of the person's social, cultural, or religious groups.
  - + At least 12 months since loss (DSM-5-TR).
- + Distinct from acute grief, MDD, and PTSD.
- + PGD is associated with increased risk for suicide (higher than MDD); and negative health consequences, e.g., cancer and cardiovascular disease (Kobak, 2023).

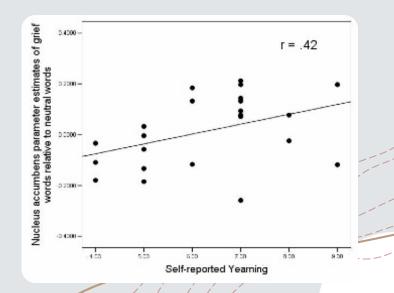
Symptoms of DSM-5 PGD	Matched item content (item number)
B.1. Intense yearning/longing for the deceased	How often have you felt yourself longing or yearning for the person you lost (1)
B.2. Preoccupation with thoughts or memories of the deceased person	Do you think so much about her/him that it is hard for you to do the things you normally do (14)
C.1. Identity disruption (e.g., feeling as though part of oneself has died)	Do you feel confused about your role in life or feel like you don't know who you are (i.e. feeling that a part of yourself has died) (6)
C.2. Marked sense of disbelieve about the death	Is it hard for you to believe that she/he is really dead (19)
C.3. Avoidance of reminders that the person is dead	How often have you tried to avoid reminders that the person you lost is gone (4)
C.4. Intense emotional pain (e.g., anger, bitterness, sorrow)	How often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to the lost relationship (2) or Do you feel bitter over the loss (9) or Are you angry about his/her death (18)
C.5. Difficulty with reintegration into life after the death	Do you feel that moving on (e.g. making new friends, pursuing new interests) would be difficult for you now (10)
C.6. Emotional numbness	Do you feel emotionally numb since the loss (11) or How often have you felt stunned, shocked, or dazed by your loss (5)
C.7. Feeling that life is meaningless as a result of the death C.8. Intense loneliness	Do you feel that life is unfulfilling, empty, or meaningless since the loss (12)  Do you feel alone or detached from other
G.G. Intense foliciness	individuals since the loss (20)

## Neurobiology of PGD

- # fMRI studies have highlighted PGD as an attachment process, beyond a cognitive stress response (O'Connor, 2008).
- + Homeostatic reward mechanisms to maintain bonds are disrupted upon loss, resulting in yearning and grief (Sadino & Donaldson, 2024).
- + From studies in humans and monogamous voles, adaptive remodeling of reward systems includes changes in oxytocin function (Arizmendi, 2023) and gene regulation (Sadino, 2023).
- + Stalling of these processes likely contributes to prolonged grief disorder.

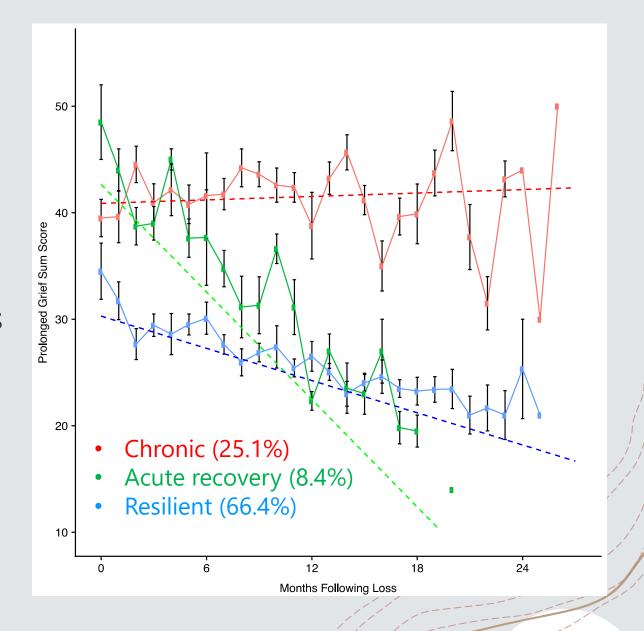


SOURCE: UCLA | GRAPHIC: Patterson Clark - The Washington Post - August 04, 2008



## Grief vs. grieving

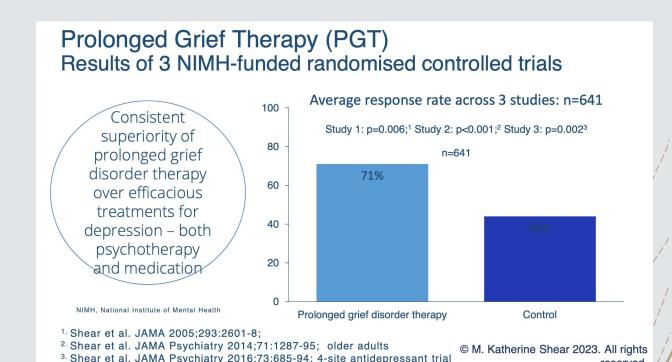
- +Research shows for the majority of bereaved people, grief decreases across time.
- + **Grief** never ends, but the trajectories of **grieving** begin to separate at about a year
- + In PGD, grief intensity and frequency does not improve, with barriers preventing the typical process of integration.



Djelantik, Robinaugh & Boelen, 2022

#### Evidence-based PGD treatment is effective

- Three NIMH-funded RCTs demonstrate efficacious treatment of PGD, compared to a proven efficacious treatment for depression.
  - + Including among older adults and in the Black community in Harlem (Shear 2005; 2014; 2016).
- + Exposure therapy is a critical component to achieve optimal reductions in PGD severity, compared to CBT alone (Bryant, 2014).
  - + This additive gain extends 2 years after treatment (Bryant, 2017).



### Grief literacy is low, even among providers

- #A critical shortage of clinicians trained in evidence-based treatment for PGD has been amplified by the COVID and opioid pandemics (Kumar, 2021).
- +Evidence-based training for prolonged grief treatment (PGT) is available (Kobak, 2023).
  - +www.prolongedgrief.columbia.edu
- +Web-based PGT training demonstrated significant improvement for social workers, psychologists, psychiatrists, both in exam and vignette formats.

## Public health approach to bereavement

Bereavement is a wider public health concern than PGD

#### **Level 0: Societal Grief Literacy & Awareness**

Public education about grief to increase the public's understanding of bereavement and support needs of bereaved persons.

#### **Level 1: General Bereavement Support & Info**

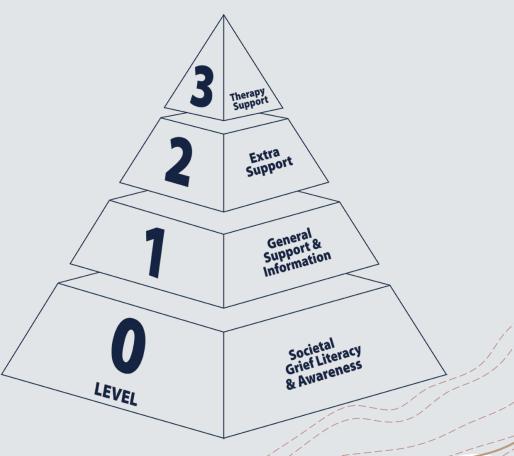
Access to information and adequate support, for example from family, social, and care networks.

#### **Level 2: Extra Bereavement Support**

Identifiable risk factors contribute to the need for additional organized support, for example in the form of peer-led groups, psycho-education in community settings.

#### **Level 3: Prolonged Grief Therapy Support**

A small portion of bereaved people will require specialist therapeutic responses, for example from trained psychologists, social workers, mental health providers



Bereavement Network Europe (BNE); NICE (UK) Bereavement Care Guidelines

#### Calls to Action

- \*National Academy of Medicine commentary (2020) Bereavement Care is Broken: A Call to Action, Joyal Mulheron & Sharon Inouye.
- + The Lancet Commission reported that "bereavement has been overlooked."
  - + Called for recentering priorities to tackle the social determinants of death, dying, and grief (Lichtenthal, 2024).
- + In 2023, Congress directed the Agency for Healthcare Research and Quality (AHRQ) to establish an evidence base and systematic review for what constitutes high-quality bereavement and grief care.
  - + <a href="https://effectivehealthcare.ahrq.gov/sites/default/files/related-files/bereaved-persons-protocol.pdf">https://effectivehealthcare.ahrq.gov/sites/default/files/related-files/bereaved-persons-protocol.pdf</a>
- + FY23 appropriations directed Assistant Secretary for Planning and Evaluation (ASPE) to write the first federal government report on grief and bereavement (forthcoming).

## Key takeaways and recommendations

- #Bereavement is a health disparity, affecting women and minoritized communities disproportionately.
- + Evidence-based PGD treatment is proven effective, though underutilized, and can ameliorate the suffering of women across the lifespan.
- + Workforce development: to understand PGD, clinicians must understand acute and typical grief—clinical training standards are needed.
- + Funding for longitudinal grief research is warranted: for basic neuroscience, clinical intervention, medical outcome, and public health studies.
- + Interventions must target appropriate groups:
  - + Research demonstrates that universally applied bereavement interventions do not achieve measurable benefit (Bonanno, 2004).
  - + A four-tier approach saves resources for when intensive intervention is needed.

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