



## PALLIATIVE CARE CASE OF THE MONTH

### How Long is Too Long? Complicated Grief Lisa Podgurski, MD

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**Case:** Ms. S is an 81 year-old woman with peripheral vascular disorder who presented with acute onset of a cold, painful, blue lower extremity and was diagnosed with an arterial clot. She was offered amputation, and in discussion with vascular surgery she declined. Palliative Care was then consulted for initiation of comfort measures, given a likely prognosis of a small number of days. The patient's daughter had been present for Ms. S's conversation with the surgeon and understood that foregoing amputation would mean her mom would die soon. Ms. S's daughter supported her mom's decision and felt it was consistent with her overall values; she also expressed distress because this was happening on top of the recent loss of her husband, which continued to occupy her thoughts a great deal. She relayed the story of their close relationship, his terminal decline, and his ultimate death, in vivid detail. In further exploration, it surfaced that his death had actually occurred 7 years ago, and that Ms. S's daughter had struggled a great deal with functioning for several years afterwards.

#### Discussion:

##### Normal Grief

*"Grief is not a disorder, a disease or a sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve."*

– Rabbi Earl Grollman

Different people respond to the death of someone close to them differently, and a wide range of responses can be referred to as "normal." Significant distress is common, and can be emotional, spiritual, cognitive, physical, and/or behavioral in nature. Some commonly-described reactions include: experiencing waves of strong feelings; disbelief that the person has died; somatic symptoms such as insomnia, palpitations, or changes in appetite; and perceptual disturbances such as visual or auditory hallucinations, or constant preoccupation with the deceased (Strada 2013). Labeling these experiences "normal" does not in any way imply that it will feel normal or comfortable for the person who is grieving. Nonetheless, for most people (90% or greater), this process will evolve over time into what is referred to as *integrated grief*, in which "the reality and meaning of the death are assimilated with a return to ongoing life" (Simon 2013). Sadness and longing

may still be present, though less intensely, and the bereaved is able to have other activities at "center stage" for much of the time. In integrated grief, symptoms may feel amplified at certain times, such as anniversaries or holidays. For most people, a transition to integrated grief occurs within 6-12 months of the death (there is still some disagreement in the literature about exact timeframe).

##### Complicated Grief

##### Diagnosis

For some people, grief lasts much longer and is more problematic. In the literature, this is most often referred to as prolonged grief, complicated grief, or traumatic grief. The DSM-5 has included the diagnosis "persistent complex bereavement disorder" as a subtype of other specified trauma and stressor-related disorders, warranting further study. There are reports that the ICD-11 will include the diagnosis "prolonged grief disorder." Along with the debate about what to call pathologic grief, there is some controversy about the exact diagnostic criteria for the condition. The DSM-5 includes three categories of proposed criteria, with at least 1 of 4 features present from Criterion B and at least 6 of 12 present from Criterion C. Put more simply, some commonly agreed-upon elements of complicated grief include:

- Separation distress, with intense longing and yearning for the deceased
- Anger and bitterness
- Shock and disbelief; Difficulty accepting that the loss has occurred
- Estrangement from others
- Hallucinations of the deceased
- Behavior change: Over involvement in activities related to the deceased or excessive avoidance.

In screening for pathologic grief in your patients, consider the use of the Brief Grief Questionnaire, a 5-item tool scored on a 0-2 Likert scale ('not at all,' 'somewhat,' 'a lot'). A score of 5 or higher warrants referral to a mental health professional (Shear 2006).

*Personal details in the case published have been altered to protect patient privacy.*

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*(Discussion Continued)*

1. How much of the time are you having trouble accepting the death of \_\_\_\_\_?
2. How much does your grief interfere with your life?
3. How much are you having images or thoughts of \_\_\_\_\_ when he or she died or other thoughts about the death that really bother you?
4. Are there things that you used to do when \_\_\_\_\_ was alive that you don't feel comfortable doing more, that you avoid? How much are you avoiding these things?
5. How much are you feeling cut off or distant from other people since \_\_\_\_\_ died, even people you used to be close to, like family or friends?

An intervention should be considered if a person has persistently high symptom severity, lack of temporal improvement in the grief response, functional impairment, treatment-seeking behaviors, hopelessness, and/or suicidal thoughts or behaviors.

Complicated grief may co-occur with other psychiatric conditions. In a recent multisite randomized controlled trial conducted by Charles Reynolds and his colleagues, two-thirds of the 400 complicated-grief patients enrolled also had major depressive disorder, and one-third had PTSD. Dr. Reynolds, an expert in this field who is here at UPMC, notes the significance of these “strong, complex patterns of co-occurring disorders” (personal communication). If a patient has persistent negative affect, endorses anhedonia, and/or suicidal ideation, appropriate treatment of depression needs to be considered.

### **Treatment**

Patients and caregivers who seem to be experiencing normal grief reactions should be offered supportive psychoeducation clarifying and normalizing characteristics of normal grief. Referral for grief counseling, such as the services offered by the Good Grief Center ([www.goodgriefcenter.com](http://www.goodgriefcenter.com)), is also appropriate.

For more extended or severe grief studies are ongoing to establish the best treatments. There are randomized controlled trials supporting the use of cognitive behavioral therapy for prolonged grief (PG-CBT) and of an internet-based therapist-assisted cognitive-behavioral indicated

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prevention intervention for prolonged grief disorder (Healthy Experiences After Loss, or HEAL) for prevention of PGD (Rosner 2014, Litz 2014). There are also studies supporting use of a targeted complicated-grief treatment, CGT, which is based on attachment theory and employs “techniques derived from prolonged exposure, IPT [interpersonal psychotherapy], and motivational interviewing.” A recent randomized controlled trial in elderly patients compared CGT to IPT, an evidence-based treatment for depression, and CGT showed significantly-better outcomes (Shear 2014).

The role for medications remains unclear, as studies have had mixed results. Patients who develop clinical depression or anxiety disorders as complications of grieving should be treated appropriately for those conditions with medications (such as SSRIs) and/or therapy. Dr. Reynolds's group will be studying whether citalopram is superior to placebo, and whether citalopram + CGT is superior to either monotherapy or placebo; results are not yet available.

If you are referring patients for psychotherapy for complicated grief, Mike Lockovich, LCSE and Claudia Dinardo, LCSW are two local therapists who worked with Dr. Reynolds in his study, both in private practice.

**Case Resolution:** Ms. S's daughter's intense and persistent grief response to her husband's death seven years ago appears to be consistent with a prolonged/complicated grief reaction. Though it might have been a feature of normal grief for her feelings to intensify with a reminder of the loss, such as her mother's impending death, the history she provides of ongoing struggle over the last several years suggests complicated grief.

Ms. S was transferred to an inpatient hospice setting for management of her pain and delirium. Prior to transfer, I made contact with the hospice agency who would be caring for her and her family to alert them to her daughter's signs of prolonged grief from a prior loss. Hospice care will include 13 months of bereavement support for Ms. S's family, and the agency's bereavement counselor planned to contact Ms. S's daughter prior to the death as well.

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