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Healing Emotions After Loss (HEAL):

Diagnosis and Treatment of Complicated Grief

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Introduction

Grief can be excruciatingly painful. As John Bowlby wrote in *Loss* (1980)¹: “The loss of a loved person is one of the most intensely painful experiences any human can suffer. Nothing but the return of the lost person can bring true comfort; should what we provide fall short of that, it is felt almost as an insult.” In this article, we review contemporary understanding of normal acute and integrated grief and its difference from complicated, or prolonged, grief. Included also are strategies for screening and diagnosis of complicated grief, together with a review of the evidence supporting psychotherapeutic and pharmacologic interventions for alleviating the anguish of complicated grief. Finally, we describe current NIMH-sponsored research to enhance the evidence base for treating complicated grief.

Normal Acute Grief

Bereavement is like an earthquake, shaking the foundations of a person's life and triggering a full-blown separation response in adults. Acute grief is a mix of trauma and separation response. Acute grief can be and usually is present most of the day, everyday, for up to six months. The experience of acute grief embodies a sense of protest, a struggle to accept the death, and an intense yearning and longing to be with the person (possibly even a wish to die to be with the deceased loved one). Bereaved people report frequent thoughts or images of the deceased, and a strong desire to reminisce and spend time with memorabilia, often at the expense of interest and engagement in ongoing life.

Pangs of deep sadness or remorse, and episodes of crying or sobbing, are typically interspersed with periods of respite and even positive emotions. A steady stream of thoughts or images of the deceased may be vivid or even entail hallucinatory experiences of seeing or hearing the deceased person. Somatic distress expresses itself with uncontrollable sighing, digestive symptoms, loss of appetite, dry mouth, feelings of hollowness, sleep disturbance, fatigue, exhaustion, restlessness, and difficulty

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initiating and maintaining organized activities. Feeling disconnected from the world or other people, indifferent, and not interested or irritable with others, all evidence the shutdown of normal exploratory behaviors.

Integrated Grief

Acute grief usually changes over time, evolving as information about the death is processed. The bereaved person is able to accept the finality and consequences of the death, reconfiguring the relationship with the deceased, and revising goals and plans for ongoing life.

As grief is integrated, the bereaved person experiences a rebirth of interest and pleasure in ongoing activities and other people, rediscovering a capacity for joy and satisfaction. While a sense of connectedness to the deceased remains, feelings of yearning, sorrow, and loneliness gradually become less intense, no longer occupying center stage.

When grief is integrated into the life of the bereaved, it becomes a permanent background state that changes in quality and importance over time. With acceptance of the death come renewed interest and engagement in ongoing life, with a mix of emotions, usually positive, and with thoughts of the deceased accessible but not preoccupying.

Feelings of emotional loneliness may nonetheless persist. Sadness and longing tend to be in the background but still present. Thoughts and memories of the deceased person are accessible and bittersweet but no longer dominant. Occasional hallucinatory experiences of the deceased may occur. Surges of grief in response to calendar days or other periodic reminders of the loss may wash over the survivor.

Progress Interrupted: Complicated Grief

In about 10 percent of people, the normal healthy progression of grief can be derailed (“complicated”), with prolongation of intense symptoms of grief beyond six months.

Complicated grief differs from normal grief because of complicating thoughts, feelings, and behaviors that derail the progress of adjustment. For example, the person with prolonged or maladaptive grief continues to ruminate about how the person died, how the loss could have been prevented, and who is to blame. He or she may engage in excessive avoidance of activities or situations that arouse intense emotions related to the loss. Ineffective emotion regulation with over- or under-engagement is common. The bereaved person feels no sense of progress, working through grief, or beginning to adjust to the finality and consequences of the death. With the prolongation of acute grief comes a sense of hopelessness that it can ever recede.

Screening for Complicated Grief: The Brief Grief Questionnaire

The Brief Grief Questionnaire (*see page 3*) allows a short (about three minutes) screening for the presence of complicated grief, with scores of 5 or higher constituting a screen-positive interview. The BGQ can be administered over the telephone. Screen positivity indicates a need for a diagnostic workup, which should be conducted face to face. It is often difficult for those with complicated grief to take the step of asking for help. Stigma, fear, and avoidance of painful affects may inhibit help-seeking and require great courage, and encouragement, to overcome.

Based upon a literature review and the factor analysis noted on page 3, we have conducted a factor analysis of ICG responses in 288 participants in previous NIH-sponsored studies.⁴ We observed a six-factor solution: (1) yearning, with preoccupation with the deceased; (2) shock and disbelief; (3) anger and bitterness; (4) estrangement from others; (5) hallucinations of the deceased; and (6) behavior change. We have used the six factors in our proposed diagnostic criteria for complicated grief (*see page 4*).

Question	Not at all	Somewhat	A lot
1. How much of the time are you having trouble accepting the death of a loved one?	0	1	2
2. How much does your grief interfere with your life?	0	1	2
3. How much are you having images or thoughts of your loved one when he or she died or other thoughts about the death that really bother you?	0	1	2
4. Are there things that you used to do when your loved one was alive that you don't feel comfortable doing more, that you avoid? How much are you avoiding these things?	0	1	2
5. How much are you feeling cut off or distant from other people since your loved one died, even people you used to be close to, like family or friends?	0	1	2

Identifying Complicated Grief: The Inventory of Complicated Grief (ICG)

The Inventory of Complicated Grief (ICG) is a self-report instrument that allows for the dimensional assessment of the severity of CG symptoms.^{2,3} Scores of 30 or higher (over a range of 0 to 76) indicate a high likelihood that the syndrome is present. Each of the 19 items is rated 0 (not at all) to 4 (severe).

- | | |
|---|---|
| 1. Preoccupation with the person who died | 11. Avoidance of reminders of the person who died |
| 2. Memories of the person who died are upsetting | 12. Pain in the same area of the body |
| 3. The death is unacceptable | 13. Feeling that life is empty |
| 4. Longing for the person who died | 14. Hearing the voice of the person who died |
| 5. Drawn to places and things associated with the person who died | 15. Seeing the person who died |
| 6. Anger about the death | 16. Feeling it is unfair to live when the other person has died |
| 7. Disbelief | 17. Bitter about the death |
| 8. Feeling stunned or dazed | 18. Envious of others |
| 9. Difficulty trusting others | 19. Lonely |
| 10. Difficulty caring about others | |

Diagnosis of Complicated Grief

We have proposed the following criteria for diagnosing of the syndrome of Complicated Grief.⁴ The DSM-5 Taskforce of the American Psychiatric Association is currently reviewing these and similar diagnostic criteria for “Maladaptive Bereavement Disorder,” as a potentially new adjustment disorder.⁵

Proposed Criteria for Complicated Grief

> The person has been bereaved, i.e., experienced the death of a loved one, for at least six months.

> At least one of the following symptoms of persistent intense acute grief has been present for a period longer than is expected by others in the person’s social or cultural environment: (1) persistent, intense longing for the person who died; (2) frequent intense feelings of loneliness or that life is empty or meaningless without the person who died; (3) recurrent thoughts that it is unfair, meaningless, or unbearable to have to live when a loved one has died, or a recurrent urge to die in order to find or to join the deceased; (4) frequent, preoccupying thoughts about the person who died, i.e., thoughts or images of the person intrude on usual activities or interfere with functioning.

> At least two of the following symptoms have been present for at least a month: (1) frequent, troubling rumination about circumstances or consequences of the death, e.g., concerns about how or why the person died, or about not being able to manage without the loved one, or thoughts of having let the deceased person down; (2) recurrent feelings of disbelief or inability to accept the death; (3) persistent feelings of being shocked, stunned, dazed, or emotionally numb since the death; (4) recurrent feelings of anger or bitterness since the death; (5) persistent difficulty trusting or caring about other people or feeling intensely envious of others who have not experienced a similar loss; (6) frequently experiencing pain or other symptoms that the deceased person had, or hearing the voice of or seeing the deceased person; (7) experiencing intense

emotional or physiological reactivity to the memories of the person who died or to reminders of the loss; (8) change in behavior due to excessive avoidance or the opposite, excessive proximity seeking.

> The duration of symptoms and impairment is at least one month.

> The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning, where impairment is not better explained as a culturally appropriate response.

Special Case: Suicide Bereavement Versus Other Bereavement

Persons who have lost a loved one to suicide may be at higher risk for complicated grief than those with other kinds of bereavement. Prominent themes in suicide bereavement encompass difficulty with meaning-making, guilt, shame, and blame (“What did I do wrong?”) and feelings of rejection, abandonment, and anger (“How could you do this to me?”).⁶ Suicide survivors often find it helpful to talk with other survivors and with family and friends who listen and don’t judge. Attending events such as the annual walks sponsored by the American Foundation for Suicide Prevention, support groups, and participation in communities of faith may help in meaning-making.

Psychotherapeutic Treatment of Complicated Grief

The guiding principles of Complicated Grief Therapy (CGT) are that grief and mourning are natural, instinctive responses that find their own healing pathway.³ Complications derive from circumstances or consequences of the death. Treatment of complicated grief can be achieved by addressing the complications and facilitating the natural mourning process. CGT revitalizes natural healing. It is both loss-focused (grief monitoring, imaginal revisiting, situational revisiting, memories and pictures, and imaginal conversation), and restoration-focused (personal goals and self-care, re-engagement with

significant others, and situational revisiting). CGT is a targeted psychotherapy combining strategies from Interpersonal Therapy, Cognitive-Behavioral Therapy (especially CBT-based exposure strategies), and Motivational Interviewing.

The one published randomized clinical trial of CG treatment³ compared Complicated Grief Therapy (CGT) and Interpersonal Therapy (IPT) for depression. Participants in the trial were at least six months post-loss, bereaved of any close friend or relative, and with ICG scores of 30 or higher. Participants were randomly assigned to CGT (n = 49) or IPT (n = 46) and offered 16 sessions of weekly treatment, over a period of up to 20 weeks. In intent-to-treat analyses, response rates (Clinical Global Impression-Improvement scores of 1 or 2) were 51 percent in CGT versus 28 percent in IPT (chi-squared = 5.07, df = 1, p = .02), generating a number needed to treat of 4. Thus, CGT was found to be effective, with a moderately large clinical effect size; however, half of participants did not respond, raising the question as to the place of pharmacotherapy for complicated grief.

Pharmacotherapy of Complicated Grief

Post hoc analyses of the 2005 CGT trial revealed that CGT was more effective when administered with naturalistically prescribed antidepressant pharmacotherapy.⁷ Antidepressant use also was associated with a significantly lower attrition rate from CGT. In an open pilot study, Simon et al.⁸ treated four patients in a 10-week treatment with escitalopram. All four patients showed a robust response with a mean reduction in ICG scores from 34.5 (SD = 6.0) to 8.3 (SD = 3) (paired t = 8.97, df = 3, p = .001). Overall, subjects decreased from markedly ill to borderline ill on average Clinical Global Impression-Improvement ratings after 10 weeks.

Ongoing Work to Expand Evidence-Based Interventions for Complicated Grief

The observations from these studies indicated that many people with Complicated Grief receive

antidepressant medication (more than 50 percent), although the evidence supporting this practice is scant. However, it is particularly intriguing that CG therapy appears to work best when combined with antidepressants, recalling a similar finding in the treatment of bereavement depression⁹ that the highest response rates were observed with combination treatment (nortriptyline + IPT).

Given the absence of any controlled medication studies for complicated grief, these observations provided the scientific and clinical rationale for a large clinical study of optimal care: “HEAL” (Healing Emotions After Loss) sponsored by the National Institute of Mental Health and the American Foundation for Suicide Prevention. HEAL is a multisite collaboration (M. Katherine Shear, MD, and Naihua Duan, PhD, Columbia University; Naomi Simon, MD, Massachusetts General Hospital/Harvard University; Charles F. Reynolds III, MD, University of Pittsburgh/UPMC; and Sidney Zisook, MD, University of California, San Diego) with three aims: (1) to obtain the first randomized controlled data about the effectiveness of an antidepressant (citalopram) versus placebo for the treatment of complicated grief; (2) to determine whether citalopram improves the effectiveness of CGT for complicated grief; and (3) to determine what the best treatment option is (antidepressant alone or in combination with CGT).

HEAL uses a 2 x 2 factorial design, with random assignment of 440 participants (including at least 40 suicide survivors with complicated grief) to one of four treatment arms, each lasting 16 to 20 weeks: (1) citalopram + clinical management; (2) placebo + clinical management; (3) citalopram + complicated grief therapy; or (4) placebo + complicated grief therapy. Pharmacotherapy allows flexible, gradual dose increase from 10mg/day to 60 mg/day over 16 weeks. The rationale for using a selective serotonin reuptake inhibitor (SSRI) is that SSRI pharmacotherapy has been shown to be effective for symptoms

of anxiety and depression (which are highly comorbid in complicated grief) and may also relieve the volume and pressure of ruminative preoccupations with the deceased.

Inclusion criteria for HEAL allow a broad age range (18 to 95) for those having experienced the death of a loved one at least six months ago, with complicated grief as their primary diagnosis, and an Inventory of Complicated Grief (ICG) score of 30 or higher. Exclusion criteria include a history of schizophrenia, bipolar, or substance abuse/dependence disorder; a Montreal Cognitive Assessment (MOCA) score of 21 or lower; active homicide or suicide risk; prior failed treatment with citalopram or escitalopram; or acute/unstable medical illness.

Summary

Prolonged, complicated grief entails suffering, distress, and disability. The experience of complicated grief is one of protracted yearning for the deceased, difficulty accepting the death, estrangement from others, absence of joy in living, and finally, behavioral changes driven by avoidance of painful affects and reminders. There are promising approaches to psychotherapeutic and pharmacologic interventions, with combined treatment showing the most promise. Research into complicated grief is still a young science, however, with important nosologic and intervention research still needed to fully understand pathogenesis and optimal treatment strategies. The attached case vignette illustrates the clinical presentation and treatment of complicated grief being provided in the HEAL Study at Pittsburgh.

Complicated Grief Case Vignette

Clinical presentation: EGD was 50 at the time of entry into HEAL, presenting with symptoms of depression, anxiety, and complicated grief related to the death of her father from cancer approximately two years ago. EGD described difficulty accepting the death of her father, with whom she “always did everything together.” She reported being unable to

shop in stores or visit restaurants which they used to frequent; at the same time she felt drawn to the area where her father spent a lot of time gardening. EGD would spend a good deal of time daydreaming about her father and reported frequent and intense pangs of grief, of yearning to be with him, with thoughts of her own death and a wish never to wake up. On the Inventory of Complicated Grief, her most strongly endorsed symptoms include longing for her father, disbelief over what happened, difficulty trusting other people since the death and feeling distant from others, and feeling that life is empty and lonely much of the time. The patient’s clinical presentation met the proposed diagnostic criteria for complicated grief. In addition, on SCID interview, she coded positive for current major depressive episode. Further medical workup, including sleep studies, disclosed untreated sleep apnea of moderate severity. At baseline, the patient’s Clinical Global Impression-Severity score was 6, indicating a severe level of distress and impairment. Her Inventory of Complicated Grief Score was 48, indicative of fully syndromal complicated grief. Her QIDS depression score was 21, consistent with current, moderately severe major depression.

Treatment in the HEAL protocol: EGD was randomly assigned to receive a course of Complicated Grief Therapy combined with double-blind pharmacotherapy (either citalopram or placebo) for 16 weeks. At the same time, she began treatment with CPAP (continuous positive airway pressure) for her breathing-related sleep disorder (obstructive sleep apnea). During the course of treatment, she had a motor vehicle accident after falling asleep while driving; as a result, we delivered her protocol treatment at her home (so that she would not have to drive) and over the telephone. She readily engaged in CGT despite finding the re-exposure components of treatment to be painful. She also was adherent to CPAP and to pharmacotherapy. Her dose of citalopram/placebo was gradually increased in 20 mg increments to 60 mg/day over the first eight weeks of treatment.

EGD improved steadily; by the end of the 16-week protocol, her Inventory of Complicated Grief score had fallen from 48 to 8. On the Clinical Global Impression – Improvement scale, she was rated at 2, “much improved”, with an overall severity rating of 3 (“mildly” ill), down from the baseline score of 6. Her QIDS depression score had decreased from 21 to 10, with residual symptoms mostly related to sleep disturbance and daytime fatigue probably secondary to partially treated sleep apnea.

Follow-up: EGD returned to her referring primary care physician with a recommendation from us to continue maintenance citalopram 60 mg daily and to have further adjustment of her CPAP to maximize therapeutic benefit. We contacted EGD six months after the end of her protocol participation; follow-up scores on the Inventory of Complicated Grief and Clinical Global Impression Severity scales indicated continued maintenance of improvement achieved during protocol.

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Contact information for clinicians interested in making referrals to the study or for those wishing to self-refer follows: (1) Boston (Nicole LeBlanc; 617-726-4585; njleblanc@partners.org; website: www.bostongrief.com); (2) New York (Rachel Fox; 212-851-2107; sw-cgte@columbia.edu); (3) Pittsburgh (Jill Houle; 412-246-6006; houleja@upmc.edu; website: www.healstudy.org); and (4) San Diego (Ilanit Young; 858-552-7598; ityoung@vapop.ucsd.edu; website: <http://psychiatry.ucsd.edu/heal.html>).

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