Treating chronic, unremitting grief

November 15 2016, by Andrea Volpe

After Stephanie Muldberg's 13-year-old son Eric died of Ewing's sarcoma in 2004, she was lost in a sea of grief. Her days were long, unstructured, monotonous. She barely left her New Jersey home. When she did leave, she planned her routes carefully to avoid driving past the hospital, just a few miles away, where Eric had been treated during the 16 months of his illness, or the fields where he had played baseball. Grocery shopping was a minefield, because it was painful to contemplate buying Eric's favourite foods without him. To enjoy anything when he could not felt wrong. And Muldberg never thought she would be able to return to the temple where he had celebrated his bar mitzvah – and where his funeral was held.

Looking back, she describes herself as not knowing how to grieve after Eric died. "I didn't know what to do, how to act in front of people – what I needed to do privately, who I could reach out to. I was fearful of making people more emotional, too emotional, and having to comfort them," she tells me, by Skype. "I didn't know how to talk about what I was thinking." Muldberg's long dark hair is pulled back and she's wearing a white T-shirt. One of the things she says is that she thought if she stopped grieving, her memories of Eric would fade, and she'd lose her connection to her son for ever.

The passage of time often seems the only remedy for grief, but time didn't help Muldberg. In the years following Eric's death, she says, she felt consumed by grief. Then a family physician heard a talk by Columbia University psychiatrist Katherine Shear about treating chronic and unremitting grief and thought Shear might be able to help her.

Four years after Eric died, Muldberg arrived at the New York State Psychiatric Institute in Manhattan, for her first meeting with Shear. She answered Shear's questions with as few words as possible. It was as if she were barely present in the small, windowless room. Her face was drawn and clouded; she sat crumpled in her chair, arms crossed tightly around her, as if the weight of her loss made it impossible to sit up straight. It felt to her as if Eric had died just the day before. Shear diagnosed Muldberg with complicated grief, the unusually intense and persistent form of grief she has been researching and treating for almost 20 years.

Grief, by definition, is the deep, wrenching sorrow of loss. The initial intense anguish, what Shear calls acute grief, usually abates with time. Shear says that complicated grief is more chronic and more emotionally intense than more typical courses through grief, and it stays at acute levels for longer. Women are more vulnerable to complicated grief than men. It often follows particularly difficult losses that test a person's emotional and social resources, and where the mourner was deeply attached to the person they are grieving. Researchers estimate complicated grief affects approximately 2 to 3 per cent of the population worldwide. It affects 10 to 20 per cent of people after the death of a spouse or romantic partner, or when the death of a loved one is sudden or violent, and it is even more common among parents who have lost a child. Clinicians are just beginning to acknowledge how debilitating this form of grief can be. But it can be treated.

I first learned about complicated grief while riding the subway in Boston, where I read an advertisement recruiting participants for a study at the Massachusetts General Hospital, which I later discovered was related to Shear's research. By then, I'd been a widow for about a decade. I was 33 when my husband died and it was fast – just six weeks from when he was diagnosed with pancreatic cancer. My grief had a different kind of complication: I was pregnant, and our son was born seven months after his father's death. By the time I read that subway ad, he was

in elementary school, and I was holding my own. I gradually went back to work. Single parenting was overwhelming, but it kept me focused on what was right in front of me. Having a young child is filled with small pleasures and motherhood enlarged my sense of community. I fell in love again. But it still felt like I walked with a limp, and that limp was grief.

Often, I felt that the course of my grief – as it slowed or accelerated – wasn't within my control. Sometimes I'd buckle, and wait it out. Sometimes I'd push back. Somehow, I knew it was going to take as long as it took. There wasn't anything to do about it except live. Freud, writing in Mourning and Melancholia, one of the first psychological essays on grief, saw it this way, too: "Although mourning involves grave departures from the normal attitude of life, it never occurs to us to regard it as a pathological condition and to refer it to a medical treatment. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful." That's how it went for me.

I'd be the first to say that my path through grief has been intellectual. I've spent years contemplating what grief is. That subway ad made me wonder: Was my grief a disease? To be diagnosed with an illness is to seek – or wish for – a cure. But conceiving of grief as a disease with a cure raises questions about what is normal – and abnormal – about an experience that is universal. Is grief a condition that modern psychology, with its list of symptoms and disorders and an ample medicine cabinet, should treat, as if it were an illness rather than an essential part of being human?

A little more than a year ago I began sitting in on clinical training workshops at Columbia's Center for Complicated Grief, which Shear directs. The first workshop was both a challenge and a relief. It was strangely comforting to be in the company of so many people – grief

counsellors, social workers and therapists – who spent their time thinking about what it meant to grieve. It would be almost another year until I called Stephanie Muldberg to see if she'd be willing to talk at length about what her treatment was like.

Sometimes I can feel in our conversations how deliberately she chooses her words. She is, she tells me, a very private person. At times her desire to talk about her experience of complicated grief feels in tension with her natural inclination to be more self-contained. "I think the problem is people don't talk about grief, and I want to normalise the fact that people can talk about it, and make it easier, and not so taboo," she tells me.

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For something so fundamental to being human, there's still a great deal we don't know about the grieving process. It wasn't until the 20th century that psychologists and psychiatrists claimed expertise over our emotions, including grief. The conventional wisdom about grieving is that it's something to be worked through in a series of stages. Lingering on any stage too long, or not completing them within a certain window of time, might be dysfunctional. Clinicians disagree about how long is too long to grieve, about whether the grieving person should wait for her grief to shift on its own or do something to initiate that process, and about what to do, and what it means, if grief is slow or stalled.

The idea of grief as something we need to actively work through started with Freud. John Bean, a psychoanalyst who has trained extensively with Shear and worked with her to treat patients in her research studies, explains to me that because Freud believed we have a limited supply of psychological energy, he viewed the central emotional "task of grieving" to be separating ourselves emotionally from the person who died so that we can regain that energy and direct it elsewhere. Freud thought this would take time and effort and it would hurt. His theory of "grief work"

persists, often in tandem with newer theories of grief.

If grief is work, then Elisabeth Kübler-Ross provided the directions for how to do it. Kübler-Ross first proposed the five-stage model in 1969 as a way to understand the psychology of the dying, and it quickly became a popular way to understand bereavement. Today, those stages – denial, anger, bargaining, depression and, finally, acceptance – are practically folklore.

But it turns out grief doesn't work this way. In the past several decades, more rigorous empirical research in psychology has challenged the most widely held myths about loss and grief.

When George Bonanno, professor of clinical psychology at Columbia University's Teachers College, researched the paths people take through grief, he discovered there's more variation to how we grieve than psychologists thought. His office, in a massive gothic brick building in New York City's Morningside Heights, is crammed with books and lined with Chinese sculptures. On a rainy afternoon he outlines the three common paths he identified. Some people, whom he terms "resilient", begin to rebound from loss in a matter of weeks. Others adapt more gradually, following a "recovery" path. The intensity of those first days, weeks and months of mourning subsides. They "slowly pick up the pieces and begin putting their lives back together", typically a year or two after losing someone close to them. People with complicated grief, like Muldberg, struggle to recover. Their grief becomes what Bonanno calls "chronic", staying at a high level of intensity for years.

One school of thought that has influenced Shear is called the dual-process model: grief is stressful, so we alternate between confronting the emotional pain of our loss and setting it aside. Even grieving people, research has shown, have moments of positive emotion in their lives. Hope returns gradually. If the stage model maps a single, clear path

through grief, then the dual-process model could be seen as a charting a wave pattern through grief.

It's now an axiom of grief counselling that there's no one right way to grieve. That seems like a good thing, but it's also a problem. If everyone grieves differently, and there's no single theory of how grief works, then who's to say that someone like Muldberg isn't making her way through grief in her own way, on her own clock? Even though it was clear to her and to those around her that, four years after her son's death, she was still suffering, bereavement researchers don't agree about how to explain why her grief was so prolonged – or what to do about it.

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Shear, who is in her early 70s, is the warmest shrink you'll ever meet. Everything about her conveys equanimity, especially the way she can sit with the stories of patients whose grief is unrelenting.

It wasn't always that way. "At the beginning," she tells me, she was "afraid to sit in the room with someone who was really intensely grieving because I was still a little bit uneasy with death and dying, but also because it makes you feel so helpless – because you feel like there's nothing you can do". The grieving person, she says, "feels like the only thing that's going to help" is bringing back the person they are grieving – "and you agree".

"Grief is not one thing," Shear says. "When it's new, it crowds out everything else, including even people and things that are actually very important to us. It stomps out our sense of ourselves, too, and our feelings of competence. We think of grief as the great disconnector, but over time, it usually settles down and finds its own place in our lives. It lets us live in a meaningful way again. It lets us have some happiness again."

Two weeks later, I'm jammed into a hard plastic desk in an overheated university classroom listening as Shear, who is professor of psychiatry at Columbia's School of Social Work, explains the underlying principle of her work, which is that "grief is a form of love".

She quotes me C S Lewis's A Grief Observed to explain what she means: "Bereavement is an integral and universal part of our experience of love. It is not the truncation of the process but one of its phases; not the interruption of the dance, but the next figure." This is called an attachment approach to grief. It's shared by many grief researchers and counsellors, and it can be traced back to the British psychiatrist John Bowlby. Attachment is what gives our lives security and meaning. When an attachment is severed by death, Shear says, grief is the response to the lost attachment. Peel back the psychological theory, and what you'll find is something that anyone who has experienced grief knows intuitively: "Nature is so exact, it hurts exactly as much as it is worth, so in a way one relishes the pain, I think. If it didn't matter, it wouldn't matter," writes the novelist Julian Barnes in Levels of Life, his extended essay on grief following the death of his wife.

Shear explains that it's our close bonds to those dearest to us that also help us want to care for other people and confidently explore the world. These attachments are woven into our neurobiology. The longing and yearning of acute grief, and the feeling of unreality that comes with it, she says, are symptoms of just how much grief short-circuits our bio-behavioural wiring.

Shear agrees with Bonanno that over time most grieving people integrate their loss into their lives. But people with chronic grief face some complicating factor. Complicated grievers tend to be women. They are often excellent carers but not so good at taking care of themselves or accepting help. Often, their emotional reserves of self-compassion and self-motivation have been drained. Shear says that "we don't grieve well

alone", but frequently people with complicated grief become isolated because their grief has remained at high levels for so long; the people around them may feel that they "should have gotten over it by now".

Shear believes that adapting to grief and loss is "a normal, natural process", she says. "We're not talking about grief itself being abnormal. We're talking about an impedance in some problem of adaptation." Think of it this way: her therapy jump-starts a stalled process, the way a defibrillator restarts a stopped heart.

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Shear's office, with its striped beige wallpaper and mahogany furniture, is so spotless it would feel like a hotel room it if weren't for the picture of her grandson as a chub-cheeked toddler on her panoramic Apple monitor. It's a sticky day in July, and she's telling me how she came to study and treat grief.

In the 1990s, Shear was researching anxiety and panic disorders at the Western Pennsylvania Psychiatric Institute and Clinic when she became involved with research on depression and anxiety in elderly people. One of the common triggers for depression in the elderly is the death of a spouse, and the team she was working with identified a cluster of symptoms in depressed patients that weren't depression. They expressed deep yearning, were often driven to distraction by thoughts of their deceased spouse, and had great difficulty accepting death, to the point that persistent, acute grief became a risk to their physical and mental health.

To differentiate grief-related symptoms from depression and anxiety, Shear worked with a research team that included psychiatric epidemiologist Holly Prigerson. It was Prigerson who, in 1995, had published a questionnaire that identified complicated grief as a specific

syndrome and could accurately assess its symptoms. Shear has relied on it as a diagnostic and assessment tool in her research ever since. Shear and her colleagues also used it to design a new treatment, complicated grief therapy. Prigerson, who now holds an endowed professorship at Weill Cornell Medicine in New York City, and directs Cornell's Center for Research on End-of-Life Care, continues to work on the epidemiology of prolonged grief.

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In their first meeting, Shear asked Stephanie Muldberg to keep a daily grief diary, recording and rating her highest and lowest levels of grief. Muldberg kept this diary for the duration of the therapy. Every day for almost half a year she was paying such close attention to her grief that it became inscribed in her daily life. Not that her grief wasn't already a pronounced everyday presence, but now, with Shear's help, she was facing it head-on rather than avoiding it. The diary was one of several techniques Shear used to help Muldberg look her grief in the eye.

Muldberg says that the grief diary helped her pay attention to herself in a way she hadn't been able to do in the four years after Eric's death. Using the diary, she began to see that she had some happy moments interspersed with some low times of grief. "There were always going to be hard times during the day for me, but I wasn't only focusing on the hard times, I was starting to learn how to move forward."

Complicated grief therapy (CGT) takes place over 16 sessions, structured, Shear says, by techniques adapted from approaches used to treat anxiety disorders, including cognitive behavioural therapy, a well-researched approach to psychotherapy, and exposure therapy, used to treat avoidance and fear in anxiety disorders. The structure itself is part of the therapy, she says, because structure is reassuring to people who are feeling intense emotions.

Shear has been testing CGT since the mid 1990s. In 2001, she and her colleagues published a small pilot study that showed promising results. Since then, they have published several randomised controlled studies supported by the National Institute of Mental Health, demonstrating that CGT helps patients who have complicated grief to reduce their symptoms better than conventional supportive grief-focused psychotherapy. Shear is a pioneer, but she's not an outlier. Currently a group therapy version of CGT is being studied at the University of Utah. Researchers in the Netherlands and Germany are also exploring variations on cognitive behavioural therapy and exposure therapy to treat traumatic and prolonged grief. And a recent study in Wales confirms one of Shear's main findings, which is that the techniques in her treatment are more effective together than separately.

A few sessions into her treatment, Shear asked Muldberg to do something she had never done, which was to tell the story of the day Eric died. It's a technique Shear adapted from prolonged exposure therapy that she calls "imaginal revisiting". At first, Muldberg says, she was apprehensive because she wasn't sure if she could remember what had happened. Over the course of three weekly sessions, Muldberg told the story of Eric's death, rating her levels of emotional distress as she did. The purpose of this technique is to "help people connect with the reality of the death in the presence of a supportive person who is bearing witness to it," Shear explains. "We want to keep grief centre stage," she says. "If you do let yourself go there, paradoxically your mind finds a way to ace that reality and to reflect on it."

Then, as with the grief diary, Muldberg had "homework": listening to a tape of herself telling the story every day between sessions. At first, this was distressing, but she gradually learned how to manage her emotions, recognising, she tells me, that she wasn't going to forget Eric. The intensity of her feelings began to lessen, so that by about halfway through the therapy she began to feel better.

Muldberg admits she was sometimes sceptical of what Shear was asking her to do, and she says sometimes she pushed back. Part of CGT includes psychoeducation, in which the therapist explains to the patient the premise and purpose of the therapy. Shear's explanations, Muldberg says, helped her understand that "there was a reason I was feeling this way". She describes Shear's approach as "I don't want to push you but we're going to figure out ways that you can accomplish these things, feel good about them, and do them."

A few weeks after Muldberg started revisiting the story of Eric's death, she worked with Shear to make a list of the places and activities she had been avoiding since he died, and gradually started trying to face them. Shear calls this "situational revisiting", a form of prolonged exposure therapy. "We do this to provide people with an opportunity to confront the reality of the loss and actually understand its consequences, because being there without the person is going to be different than being there with the person. We want people to start to reflect on that," she tells me.

For Muldberg, many of the things she had avoided were the everyday parts of being a mother, such as going to the grocery store, but she says, "I didn't realise how much harder avoidance was than doing some of these things." Together with Shear, she broke down tasks, such as driving past the baseball field where Eric had played, into smaller steps until she could do them again.

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Sitting in that classroom listening to Shear explain these exercises makes my chest tighten until my heart aches. I can't imagine doing them myself, let alone how anyone with complicated grief could withstand them. It seems like a wrenching exercise in repeatedly tearing a scab off a wound.

When I ask Shear about this she acknowledges that her approaches are counter-intuitive because they "ask people to go toward their grief". She tells me it's by explicitly detailing and describing their grief that people with complicated grief become unstuck, as they learn to shift back and forth between the pain of grief and restoring their lives. Shear is more interested in having patients engage with the therapy techniques than she is with getting them to reach a certain point. To her workshop audience, she puts it this way: "We do not try to lower grief intensity. I'm just trying to turn the Titanic one degree."

In one of my conversations with Muldberg, I remark that CGT seems counter-intuitive, almost confrontational, and that these exercises seem extremely emotionally demanding. She is quick to correct me. Therapy was challenging, she says, but it came as a great relief to finally feel understood and have the support to face Eric's death. "When I started to do things, I started to feel better," she tells me.

For Shear, "feeling better" is a sign that our natural adaptive abilities are kicking in, allowing a person who is suffering from complicated grief to begin the emotional learning process that ultimately helps grief subside. This also creates an opening for the person to begin to reimagine their life after a devastating loss.

At the same time that Shear was helping Muldberg come to terms with the reality of Eric's death, she was also helping her begin to envision the future. Part of losing someone very close, Shear says, is that we lose our sense of identity. Part of grieving is regaining it.

In another CGT exercise, the therapist asks a scripted question: "If someone could wave a magic wand and your grief was at a manageable level, what would you want for yourself? What would you be doing?" Someone with complicated grief can't imagine a future without the person they've lost, or without the unrelenting, intense grief that's taken

up residence in their life. It's a future-oriented question for someone who has lost sight of the future. Just asking the question, Shear says, can activate our innate exploratory system and spark hope.

One way to think of the therapist's role in CGT is that she's teaching her patient what grief is. "Loss is a learning process. The problem is, it's unwanted information," says therapist Bonnie Gorscak, one of Shear's long-time collaborators and a clinical supervisor at the Center for Complicated Grief. Learning from loss, Gorscak says, means being able to "stand in a different place and look at grief", to approach the pain it causes, experience it, and have some respite from it. It's a counter-intuitive approach for therapists, too. Sitting with someone with complicated grief, Gorscak says, "is some of the worst pain I've ever sat with".

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CGT is challenging, but it works. Still, Shear's therapy has sparked controversy, starting with the very idea that there is a form of grief so severe and debilitating that it meets the definition of a mental illness.

In recent years, Shear and a group of colleagues have advocated for a grief disorder to be included in the Diagnostic and Statistical Manual (DSM), psychology's diagnostic bible, because they believe complicated grief is a clear-cut, diagnosable syndrome, separate from depression, anxiety or post-traumatic stress disorder. (Shear and Prigerson, once collaborators, now disagree about the best way to diagnose complicated grief, but they agree it should be viewed as a mental disorder.) Without sanction by a DSM diagnosis, psychotherapy in the US is not covered by health insurance. Without insurance reimbursement, CGT is out of most people's reach. In 2013 the DSM-5 listed Persistent Complex Bereavement Disorder as a "condition for further study", calling for more research on the issue.

The major issue therapists have with complicated grief is that they believe it pathologises a fundamental human experience. Leeat Granek, a health psychologist at Israel's Ben-Gurion University, is concerned that including a grief disorder in the DSM could narrow the spectrum of acceptable ways to grieve and create a narrative that would distort the ways people understand their own grief. She believes that this would lead to "a lot of shame and embarrassment for the mourner because the expectations around grief are no longer realistic".

Donna Schuurman, senior director of advocacy and training at Portland's Dougy Center, which supports grieving children and families, questions the idea of a grief disorder. She rejects the use of terms such as "complicated", "debilitating" or "persistent" to describe grief reactions and as the basis for constructing a diagnosable syndrome. Schuurman agrees that "grieving people may have chronic issues or chronic problems related to what has happened after someone dies", but says that "often those issues were already there before the death", and that "chronic issues ought not to be framed as mental disorders of grief".

"Medicalizing or pathologizing the experience of someone who is having difficulty after a death does not do justice to the full social and cultural context in which he or she is grieving," she writes. "Grief is not a medical disease, it is a human response to loss. Many people who are experiencing severe challenges after a loss are doing so because the social expectations around them are not supporting them."

Instead of labelling complications of grief as symptoms that define a disorder, Schuurman says she would focus on the experiences and behaviours that were contributing to any "serious challenges" a grieving person was facing. "We can label it depression, drug or alcohol abuse, etc., as any good therapist should do," and "try to look at underlying issues, and not just symptoms, to be of help," she explains. Good professional help, she believes, "could take a variety of forms and

theoretical backgrounds".

New scientific research on grief, Shear's among it, is challenging some of the foundational premises of grief counselling as it has been practised, often in community settings. As George Bonanno discovered, there are several common trajectories through grief, meaning that there are some commonalities among grieving people as they adapt to loss. Still, Shear says, "each experience of grief is unique, just as each love experience is unique". CGT, she says, "helps people find their pathway to adapting to loss".

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One way to answer the question of whether or not grief is a disease is to ask if the treatment provides a cure. Stephanie Muldberg describes her grief as "a wound that wasn't healing", but CGT isn't a cure the way antibiotics cure an infection. Grief doesn't end, it just changes form. Muldberg says CGT taught her how to live with grief as part of her life. She still carries her grief for Eric with her, but she is also back in the world. She travels with her husband and daughter. She volunteers for the Valerie Fund, an organisation that supports families of children with cancer and blood disorders, and that helped Eric and their family when he was sick.

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I ask Shear when her fear of sitting with intensely grieving people had subsided. "Well," she says, "there's this entire field of study called terror management." I was expecting her to tell me about her feelings but she answers by telling me how research explicated them – exactly what she's done in designing a therapy for complicated grief. I look up terror management: it's the theory that in order to deal with the fear of our own mortality, we find ways to find meaning and value in our lives – like

helping people. In that sense, what Shear has done with CGT is to create a form of evidence-based compassion. It's compensation, perhaps, for the existential helplessness of the therapist, but it also compensates for many of our communal failures helping people grieve. We are too busy, too secular, too scared to deal with grief. It's hard for Western culture – American culture in particular – to sit with something that can't be fixed.

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The more I thought back over my conversations with Stephanie Muldberg, the more I thought about how her therapy with Shear helped her put Eric's death in context of her life story. The idea that a story needs a beginning, middle, and end goes back to Aristotle. People with complicated grief can't see the arc of their own stories. They can't get to what classic plot theory calls denouement – resolution. Most of us, when faced with a loss, find a way of putting what happened into the form of a story: this is what happened, this is who I was, this is what the person who died meant to me, and this is who I am now. But people who have complicated grief can't do this.

Grief is a problem of narrative. A story, in order to be told, needs a narrator with a point of view who offers a perspective on what happened. But you can't narrate if you don't know who you are. Many of Shear's therapy techniques are about learning to narrate in the face of great pain and devastating losses. Start with the grief diary, which records the emotional story of your everyday life. Follow that by imaginal revisiting, akin to a wide-angle shot in cinema, which helps organise a story arc amidst intense emotion.

Plotting out the story restores the narrator and the narrative. Then, you can begin to imagine a new story, a new plot for yourself. It's not a choice between grief or living, remembering or forgetting, the way Muldberg once worried it was. The book of life is a multi-volume set. A

sequel can only start when the first volume is brought to a close and when the narrator knows she's going to be all right.

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