
Narratives of grief and their potential for transformation

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(RECEIVED November 21, 2005; ACCEPTED January 29, 2006)

ABSTRACT

This article examines narratives of grief and loss and how, under the best of circumstances, they may lead to transformation and growth, even contributing to the greater social good. Using psychodynamic and narrative theories, and examples drawn from mourners who have used their grief in powerful and political ways, I make the case that even grief that has been highly appropriated and contested, as in the case of Terri Schiavo, may ultimately serve important functions. Grief may mobilize mourners by helping them to turn passivity into activity. Grief may mobilize higher-level defenses such as altruism. Grief and loss may lead to a mourner's desire to do for others what was not done for him or her. A necessary part of turning grief into social action is the creation of a coherent grief narrative—first personal and then political. This coherent narrative can be developed using clinical interventions as well. Hence I discuss the clinical implications of helping those who are grieving to create coherent narratives out of shattered assumptions in a process of personal and social change.

KEYWORDS: Grief, Coherent narrative, Transformation, Altruism, Political and social action

INTRODUCTION

When we were organizing the Schiavo conference, we received uniformly positive responses, except for one e-mail, which asked why we couldn't just leave Terri Schiavo alone now that she was dead. The e-mail asked why we had called the conference "Lessons from Terri Schiavo." The answer was that we, as a group, were engaged in processes of meaning reconstruction as we tried to make sense of her life and her death, collectively and constructively. This process of meaning reconstruction, or the creation of a coherent narrative, is normatively an important part of grieving and one that deserves further attention.

Terri Schiavo's life and death were very public, politicized events, and both were widely appropri-

ated by conflicting interest groups. Her life was framed by the religious right as a right-to-life issue and by the moderate and left wings as a right-to-die issue. Some in the federal government used her story to broaden federal powers in relation to individual and states rights. Disability groups claimed Schiavo as their cause (Jeserich, 2005), and one disability group, Not Dead Yet, appropriated Schiavo's life and death to warn that the removal of her feeding tube would foreshadow routinely removing life-sustaining treatments for persons with muscular dystrophy, brain damage, and Alzheimer's disease. The Terri Shindler-Schiavo Foundation (2005) was incorporated to financially support the Shindler family's cause during the time that she lived in a persistent vegetative state "to advocate, protect and provide care for people with disabilities, to recognize the dangers associated with end-of-life decisions and to provide the tools necessary for families to address these decisions with the committed belief that all human life is sacred." The Life

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Legal Defense emerged, while Terri was living, as a fund that paid more than \$15 million in donations to support Schiavo's parents, the Shindlers. The Family Research Council used part of its \$10 million budget to file an amicus brief on the Shindler family's behalf (Bowers, 2005). The Vatican weighed in on her life and death by condemning the withdrawal of her feeding tube as murder (Rizzo, 2005). The Ave Maria University in Naples, Florida, gave a scholarship of \$4 million in the name of Terri Schiavo (CBS47, 2005) to students studying for the priesthood. Other religious groups claimed that the withdrawal of nutrition and fluids violated Schiavo's constitutional right to the free exercise of religion. The group Let Terri Live authored her story as being one of family values (Drake, 2005). The American Civil Liberties Union, on the other hand, argued persuasively that the governor of Florida and the legislature of Florida, as well as the federal government, overstepped their bounds by overruling the courts, which had maintained that her husband, Michael, was her legal guardian (Arons, 2004).

As for her husband, Michael Schiavo, he was called an abuser, a self-centered man who sought his wife's death, and even likened to Hitler. Another narrative maintained that Schiavo died of starvation because her adulterous husband wanted to devote himself to his new family. Contrasting with these narratives were those that maintained that Schiavo's husband was a hero, and that the desire to discontinue her feeding tube was borne out of love and respect for her wishes (Eisenberg, 2005).

How did Terri Schiavo's death become so multiply storied, advancing political agendas on the left and on the right? Even more importantly, what actually were the stories of the mourners—her parents, her siblings, and her husband? How did their mourning narratives also become part of the public discourse on the right to life and the right to die? Were their narratives things that were politicized by others or were they also a form of their own social action in the face of their personal loss and grief?

In preparation for my presentation at the Schiavo Conference, I followed up with the lawyers of both the Schiavo family and the Shindler family to learn about how, from their perspectives, the families were handling their grief. Both lawyers told me that the Shindlers and the Schiavos were doing well, were currently under contract to write books about their experiences, and that each family has been active politically, continuing to advocate either for the right to life or the right to die (J. Eisenberg, pers. comm., 2005). The Shindlers' son, Bobby, has left his full-time teaching job to raise money for the organization, Terri's Fight, and his

sister and parents are writing a book. Michael Schiavo has been on the road, making political speeches and even appearing on talk shows. He also has a book forthcoming in March 2006. According to their lawyer, the Shindlers were particularly comforted by their meeting with Pope John Paul II.

Hence, I began to wonder whether grief, loss, and bereavement—however public and contested they may be—are routinely used in the service of creating a meaningful narrative for the mourner. Not only might the mourner need to create meaning, but, in fact, those who are mourning often work to change social conditions. Can it be that some grief narratives can be transformative, changing the mourner's self, ideals, and ongoing relationships with the dead? Might the Schiavo and Shindler families, then, be doing what many individuals and families do with their grief—that is, creating coherent narratives in the service of activism and social change?

In this article, I maintain that grief and bereavement hold the potential to change the mourner—who she is and who she hopes to become—even ennobling the mourner to contribute to the greater social good, to activism, and to social change. Hence, I only address the largely positive aspects of grief and mourning and the ways in which grief has the potential to transform the mourner's loss into, first, a personal narrative, and, then, a political narrative.

The literature on grief and mourning has overly emphasized the negative and even pathological consequences of grief, often conflating mourning with depression and assigning to grief a set of diagnostic labels (Lindemann, 1944; Middleton et al., 1993; Jacobs et al., 2000). There are many forms of grief that are difficult to resolve. One explanation is that complicated grief arises from unconscious anger toward the deceased (Freud, 1917). Another is that grief may be experienced as a devastating blow to self-esteem (Bibring, 1952) or the mourner's developmental level may be such that the capacity for mourning is compromised (Klein, 1940; Bowlby, 1961, 1963) or the attachment style (Ainsworth et al., 1978) of the mourner may be too disorganized for the mourner to be able to fully experience the complexity of the loss. However, for those who are more able, there are also more hopeful aspects to grief and loss.

There are many examples of how grief and bereavement provide opportunities to find coherence, changing the mourner's self, ideals, and ongoing relationships with the dead (Harvey et al., 1996; Neimeyer, 1997, 2001). In the best of circumstances, what may be traumatic, overwhelming, and incomprehensible at the time of death, may, over time, coalesce into a set of meanings (Aronson, 2004).

In this article, I give a series of examples of the kinds of transformations that can arise from grief, so that the personal may become political for the person who is grieving. Next, I discuss the nature of meaning reconstruction, which is essential to mourning. Third, I consider how creating a coherent grief narrative out of a loss helps the mourner to move from passive to active and to mobilize, under the best of circumstances, a sense of purpose and even the defense of altruism. Finally, I talk about the clinical implications of claiming one's own grief experience and weaving it into something coherent in order for others to suffer less.

REVIEW OF THE LITERATURE

Avery Weisman (1974) once said, "That we can thrive under inauspicious occasions is really quite remarkable" (p. 6). The death of a loved one, normatively, is often a very inauspicious occasion, and yet it is one from which we may not only survive, but thrive.

Freud was the first psychological theorist to think about how loss and grief change the mourner. He thought that mourning was not necessarily a pathological condition, though it often feels that way (Freud, 1917). Freud was interested in how loss and grief initially deplete us, empty us out. In his view, mourning often feels like dejection and exhaustion. A part of this exhaustion, he thought, occurred because, when a loved person dies, the mourner naturally withdraws his or her energy from the outside world while focusing on the nature of the loss. The mourner is preoccupied with memories of the person who has died and is caught between holding onto and letting go of the object of his loss. Often a mourner will try to hold onto the person who has died by telling his or her stories again and again, looking at photos that memorialize the person, wearing the clothes of the person (Volkan, 1981), playing the person's music, preparing her foods, holding conversations with the person, setting an extra place at the table, and ruminating about the terminal circumstances that surrounded the death.

Freud referred to this process as hypercathexis. Ira Gershwin more accurately described this state in which the mourner tenaciously holds onto the memories of the dead in a song that he wrote for his brother who died of a brain tumor: "The way you wear your hat; the way you sip your tea. The memory of all that. You can't take that away from me." Here, Gershwin was demonstrating how, in mourning, each memory of the person who has died is full of meaning. Mourners recall, tenaciously, the object of their loss, ensuring that those memories will be

held. Those who are mourning also keep alive the persons they have lost as a means of maintaining ongoing relationships with them (Silverman, 2004).

Joan Didion, in an effort to make sense of her husband's death from sudden cardiac arrest, recently wrote in the *New York Times*:

Later I realized that I must have repeated the details of what happened to everyone who came to the house in those first weeks, all those friends and relatives who brought food and made drinks and laid out plates on the dining room table for however many people were around for lunch and dinner, all those who picked up the plates and froze the leftovers and ran the dishwasher and filled our otherwise empty apartment even after I had gone into the bedroom and shut the door. Those moments when I was abruptly overtaken by exhaustion are what I remember most clearly about the first days and weeks. I have no memory of telling anyone the details, but I must have done so, because everyone seemed to know them. At one point I considered the possibility that they had picked up the details of the story from one another but immediately rejected it: the story they had was in each instance too accurate to have been passed from hand to hand. It had come from me. (Didion, 2005, p. 146)

No one, Freud wrote, ever abandons a libidinal (loving) position willingly, even when another beckons. Consequently a mourner will not easily fall in love again. Grief takes immense energy. Didion again writes:

[There is] a difference between grief as we imagine it and grief as it is, the unending absence that follows, the void, the very opposite of meaning, the relentless succession of moments during which we will confront the experience of meaninglessness itself. Grief is different. Grief has no distance. Grief comes in waves, paroxysms, sudden apprehensions that weaken the knees and blind the eyes and obliterate the dailiness of everyday life. (Didion, 2005, p. 146)

But Freud (1917) thought that with the passage of time and with an increasing capacity for reality, the mourner would slowly "decathect" his energy from the person who had died, and that this would free up new energy in order to reinvest in the world. Taken literally, Freud posited that we ultimately divest our energy from a person who has died in order to be able to love again.

Later in the same paper, however, Freud provided another explanation for how we accomplish

this task. In one of the first object relations concepts to enter into the psychoanalytic discourse, Freud explained that “the shadow of the object falls upon the ego” (Freud, 1917). By this he meant that the survivor’s ego is always shaped by the person who has died and that the shadow of that person comes to inhabit parts of the self. In *The Ego and the Id*, Freud (1936) wrote about the important function of identification in mourning and about how aspects of the lost other are identified with and come to reside, unconsciously, inside of the self. The capacity to take in and internalize aspects of those whom we have loved as parts of ourselves may enrich or deplete the ego. But the capacity to take in valued aspects of a person who has died ultimately makes grief bearable. I would add that this potentially makes grief transformative.

Let us consider some examples of how the shadow of the object falls upon the ego and how it shapes the mourner through identification with the attributes of the person who has died. Take, for example, the 56-year-old mother of a 31-year-old writer who died of stomach cancer. A hospital administrator, the mother began in her grief to write short stories and poetry and to publicly read her work for the first time. Her stories and poems began as texts about her son, but later addressed a range of topics. In the face of her son’s untimely death, his talents and skills became her own. They altered her sense of self and identity and reshaped her career and purpose in life.

Or consider the widow of a senator killed in a plane crash whose identity was transmuted by her husband’s death. After his death, she took on his role as a senator and later ran her own senate campaign. Not only had the identification with her husband shaped a new sense of self and identity, but she, like the mother whose son had died of cancer, developed a range of new ego capacities that were not formerly accessible.

Consider the mother of Vicky Runnion, a four-year-old child who was kidnapped and brutally murdered. Vicky’s mother had previously led a quiet and private life. But in her grief, she mobilized as an advocate for kidnapped children nationally and worked publicly to provide safety education for parents so that others might not repeat her tragedy.

Or consider the widow whose husband died of cancer and who then started a business of knitting intricate scarves. Although she might have been weaving together new materials with the old in a symbolic way, her first foray into the world of non-domestic work proved to be robustly profitable. Rather than keep her profits, however, she donated them all to the hospice that had cared for her beloved husband.

We are all familiar with the 9/11 families, ordinary people who lost spouses, siblings, parents, and children. These same ordinary people have testified in Congress about lax security, fought for memorials that appropriately reflect their grief, and have spoken out about the war on terrorism and its failures. They became extraordinary through their grief.

Or we can think about the Rosenberg children, two boys, ages 2 and 6 in the 1950s when their parents, Ethel and Julius, were alleged to be spies and put to death. Although these young boys were visibly in the news during their parents’ trials, imprisonment, and in the many protests against their parents’ pending executions, both boys disappeared from public view after their parents’ deaths. The two boys were ultimately adopted and led quiet lives. However, in early midlife they began to speak out about their parents’ unjust trial and executions and began a charitable foundation. The Save the Children Foundation now serves and protects the rights of other children whose parents are victims of political persecution.

Another example is offered by Susan Komen’s sister, Nancy Brinker, who made a promise to her dying sister that she “would work to spare other women from suffering in the same way.” In a recent article in *Business Week*, the author writes:

Having no fortune of her own, she needed a way to both raise money and draw attention to the cause. The novel solution which she arrived at while jogging was to start a series of five-kilometer charity runs named Race for the Cure.

Such events are now ubiquitous, but in 1983, Race for the Cure was one of the first. And it has become one of the largest. Since its inception, the Komen Foundation has collected more than 630 million dollars for breast cancer research, education, screening, and treatment and is considered a prime mover behind the progress in treatment since the 1980s.

Brinker says, “I told my sister I would change this if it took me the rest of my life.” The foundation has given out over 180 million dollars for research. “There is hardly an advance in the science of breast cancer that hasn’t been touched by a Komen grant. That’s what I am most proud of,” says Brinker who survived her own bout with breast cancer. To honor her work, Brinker was awarded the very prestigious Mary Woodward Lasker award for Public service, yet Brinker says her promise to her sister is still yet to be fulfilled.

"We remain focused on one thing," Brinker said, "a world without breast cancer. We will continue to address causation as well as the disparities in treatment in medically underserved populations." (Arnst, 2005, p. 24)

What is going on here? Might these personal and then political activities reflect the shadows of the dead as embodied in the living? It would appear that each of these mourners not only engaged in processes that altered their selves and their egos, but also that they took on the values and ideals of the person or persons who had died.

As Freud maintained that the ego is shaped by the loss of significant others and by their internalizations, Loewald added a further dimension to understanding how loss and grief transforms the mourner and leads to changes in a person's conscience and ideals. In a paper on separation, loss, and the superego, Loewald (1962) suggested that losses change not only the survivor's self but that the survivor's conscience and ideals are also changed through identification with the values of the person who has died. In grief, the mourner identifies with the ego ideal of the deceased and this alters the mourner's own purpose and ideals.

Another example is provided by the parents of Amy Biehl, a brilliant Stanford graduate who was murdered while on a Fulbright Scholarship in South Africa. She had gone to South Africa to work against apartheid. After her death, her parents returned to South Africa as part of the Truth and Reconciliation Act. There they confronted her four African murderers with the facts of Amy's life, while simultaneously forgiving them for the death of their child. In their testimony before the Truth and Reconciliation Committee, they conveyed to the men who killed their daughter her ideals, now theirs, to further the cause of social justice in South Africa (Biehl & Biehl, 1998).

Ted Kennedy was a wild, irresponsible young man with a poor academic record—the least achieving of his four brothers, and the least interested in politics. Over the course of losing one brother in WWII and two brothers to assassinations, we might wonder about their role in Kennedy's subsequent commitments in the Senate to advocate for and support the most disenfranchised. Ted Kennedy might be understood to have assumed his brothers' ideals and values, which altered not only his ego, but his superego.

Freud was correct, then, that grief and loss do empty us for a time, depleting us in waves and paroxysms. But mourning also has the potential to transform who we are and who we want to become. Loss and grief may be healing when they lead to

changes in self-concept, character, and ideals, as well as in a renewed sense of commitment to something greater than ourselves.

Robert Neimeyer (1997, 2001) would conceptualize the move from unbearable grief to meaning making and social action as being an important transition, which requires that the mourner engage in meaning reconstruction. Rather than the mourner being a passive recipient of the death experience (Baker, 2001), bereavement offers the mourner new ways to construct personal, familial, cultural, and political meanings that are highly variegated. Silverman (1988) would add that the mourner never gives up the person who has died. Instead, she engages in continuing bonds with that person, changing for as long as she lives her view of herself and of the person who has died. Rather than experiencing end points to grief, people who grieve are always making new adaptations and changes in relation to the dead. We do not sever our ties to the deceased, but rather remain in continuous relationship with them. They live inside of us, shaping who we are, who we seek to become. With loss, a sense of meaning may be shattered; but with meaning reconstruction, there is the possibility for new adaptations and new behaviors.

Under the best of circumstances, death may offer the mourner the opportunity to turn passive into active and to mobilize altruism, one of the most adaptive defenses (Vaillant, 1979). Both of these processes involve the mourner in doing for others what could not be done for them. There are, in death and bereavement, many forms of coherent narratives that may be created that allow the mourner to become more active and altruistic. And although not everyone runs for a senate campaign, works for peace and justice in South Africa, mobilizes for child safety, or becomes a writer, there are small but significant ways in which ideals may change after a significant loss.

CLINICAL IMPLICATIONS

Clinically, there is value in helping clients who are grieving to identify with the values, strengths, and attributes of the person who has died. Although this may happen in individual work, it is accelerated in groups (Itin et al., 2004; Sutton & Leichty, 2004) where clients tell their stories and begin to develop more coherent narratives in the context of hearing others' stories. Loss groups have the potential of helping the bereaved change their inner, interpersonal, and outer worlds. Mutual self-help groups (Silverman, 1986), where grief and loss are de-pathologized, are particularly useful venues. People with similar experiences can begin to encourage

each other to shift from passivity to activity, mobilize adaptive capacities, advocate for others, foster resilience, engage in social action, and do for others what was not done for them or the person who has died.

Another form of helping the bereaved to develop coherent narratives may occur through the creation of memory books or other symbolic forms of disruption and repair. I recently spoke at Bo's Place in Houston, Texas, which is a child bereavement center set up by the parents of a 12-year-old boy who died of leukemia. There, I was struck by a project that every grieving family completes as they leave the agency. Each family is presented with the shards of a pot; the family's job is to put the pot back together. Inevitably, there are pieces missing, and the pot will have holes and parts that are absent. But in the course of trying to put back what was shattered, families do their best to come to terms with what can be repaired and what will forever be imperfect and unfixable. In family camps for children with a parent who is dying or has died of AIDS (Itin et al., 2004) or cancer, members construct memory books—composites of pictures, sayings, and shared experiences—that, after the person has died, leave a legacy for the survivors, who can view the book when they return to camp.

CONCLUSION

If, as practitioners, we can understand that loss and grief may lead to changes in the mourner's self-concept, character, identity, ideals, values, coherence, perspective, and commitments, then we can begin to appreciate how possible it is to, in fact, thrive under inauspicious conditions.

Terri Schiavo's parents, husband, and siblings are now in the process of creating their own narratives, their own meanings—each constructing a new sense of themselves. Their narratives are personal, and they are political. In the midst of the battles over medical, legal, ethical, and religious perspectives, it is their own stories that they are writing in the hopes of changing the conditions of dying in America as they see them.

In a case chillingly similar to Terri Schiavo's, 25-year-old Nancy Cruzan sustained life-threatening injuries from a car accident that left her in a persistent vegetative state. Five years later, when she had still not emerged from her coma, her family requested that her feeding tube be removed so she might die of her natural injuries. Like the Schiavo case, Nancy Cruzan had not signed an advance directive. Although her family was allowed to uphold the right to discontinue her feeding tube, the state of Missouri overturned the ruling, arguing

that there was not clear and convincing evidence of Cruzan's wishes. In 1990, the U.S. Supreme Court, by a 5-to-4 majority, established a precedent for Cruzan's constitutional right to die. New evidence was provided of Nancy's wishes, and a court order allowed the Cruzan family to discontinue her feeding tube. She died on Christmas Day. This landmark case also changed the face of dying in America.

As with Terri Schiavo, a media frenzy accompanied the family's suffering. Their anguish was "broadcast over the public megaphone of law and made into the subject of almost endless media attention and public debate" (Arons, 2004). According to William Colby, Cruzan's devoted young lawyer, Nancy's father, Joe, committed suicide 6 years after his daughter's death, by hanging himself in the carport. He left a note to his wife and family that read, "I hope you find peace in your new house. And I can [*sic*] find, too. I love you all. I love Nancy and am sorry about what happened." In his eulogy for Joe Cruzan, William Colby wrote:

The psychiatry books are filled with analyses that tell us that a parent who loses a child suffers the single greatest trauma a human being can experience. It is well documented that many parents never recover. But there is no book to tell us the depth of wound suffered by a parent who loses a child to permanent coma, stays with that child night after night, year after year and when recovery does not come, that parent must then fight a highly public battle to free that child from unwanted medical technology with the ultimate outcome, seven tortuous years after the accident, of winning the right to allow that child to die. (Arons, 2004, p. 397)

Like Nancy Cruzan, the Schiavo death was played out on every stage: societal, political, legal, medical, religious, and personal. Both families lost a daughter, and both families lost their privacy. Both families suffered highly public grief and bereavement. Further work is needed to explore why some families are able to create coherent grief narratives, whereas others are simply not.

Grief and bereavement can teach us lessons about living, and they can offer us opportunities to make coherent what may have been incomprehensible before. Grief can, under the best circumstances, change who we are, how we live, and even the social conditions in which we live. But the creation of a narrative is not always possible, nor is every narrative one that becomes political. Nonetheless, as we try to make sense of Terri Schiavo's life and death, we may also be creating meanings that improve the quality of end-of-life care in this country.

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