

Chapter 2

Narrative Accounts of the Agony of Suffering

2.1 The Significance of Narratives of Pain and Suffering

A narrative is a story that has a teller, a listener, a language, characters, plot, and the dimension of time. Narratives and suffering have a long, common history; in fact, healers, doctors, and other health care workers have little else on which to base diagnoses of pain or suffering than their patients' words. A personal story often yields important details, which is why Charon (2005) argues that story telling is essential for treating pain and suffering: "illness calls forth the self... and the self is knowable only through stories." Charon coined the term "narrative medicine", and she regularly trains healthcare professionals in the use of narrative methods, especially in the treatment of those burdened with chronic pain and suffering.

While in medicine most insight-bearing narratives are spoken, written stories are helpful for difficult diagnoses. The physician or therapist may not be able to understand how to best interpret the essential facts and related events without writing up his or her own notes and then studying them. Likewise, the person suffering may be asked to write; the sufferer may gain important new self-insights and provide new information for diagnosis. Charon (2005) believes these stories are central to effective pain treatment, underscoring the importance of close partnerships between patient and physician, of authenticity in both roles, and of recognition of the mutuality of suffering. Clinicians suffer as they empathize with their patients' suffering, and they, too, need to learn how to accept suffering, not deny it.

Still, healthcare professionals working with patients quickly learn that of the close relationship between suffering and quality of life (Niv 2005). Narratives add details about small adjustments or even radical shifts in one's quality of life. They also suggest how one's daily life, relationships, and social context increase or decrease the experience of suffering. Niv (2005) asserts that, because a huge (e.g., 20 %) share of the United States population suffers from chronic pain and suffering, most healthcare professionals take for granted an understanding of the quality of life changes among those treated for chronic pain or suffering.

2.1.1 Authenticity of Narratives of Pain and Suffering

Unfortunately, narratives cannot always be taken at face value. They may be falsified or exaggerated for various purposes. Morphine-based pain medications and other pain reducing drugs are illegal without a valid prescription in many jurisdictions, and they have a high street value. Sometimes scammers will use stories to make fraudulent insurance claims and get prescriptions from doctors.

Other fraudulent narratives are fabricated memoirs. A few years ago, several best-selling memoir authors were exposed as having embellished stories of great pain and suffering that were presented as ‘true.’ Essentially, the wide audience for such stories created a genre called ‘misery lit.’ Book publishers and television producers have taken advantage of the morbid motivation of many consumers to identify with others who suffer from pain and other calamities, and some have overlooked fraudulent narratives.

Illouz (2003) conducted an extensive analysis of Oprah Winfrey’s talk shows and concluded that Oprah had created a “multilayered textual structure that initiates, stages and performs narratives of suffering and self-improvement, resonating with a wide audience.” Using sophisticated discourse analysis, Illouz shows how Oprah used stories such as celebrity tragedies to not only entertain her audiences but also help them make sense of suffering. The stories were meant to give viewers an illusion of being ‘on track’ toward a more authentic identity. One tactic in this message, Illouz asserts, is the story of victim culture, which legitimizes large payouts by insurance companies and other institutions. This victim culture anesthetizes us to character corrosion (Senett 2000) and makes fabrications seem less than harmful. They may even seem like a form of ‘deeper truth.’

Thus, while there are both personal and institutional pressures for contemporary stories to use suffering in inauthentic ways, the actual prevalence of authentic pain and suffering remains high, even growing. Surveys of pain and suffering reveal tremendous suffering worldwide, including in the wealthier nations.

2.2 Narratives of Suffering on the Internet

Because of its enormous storage capacity and active use by over 85 % of people in most age groups, the Internet, commonly known as the Web, has become a microcosm of human society. Its content represents most of the dominant cultures in developed societies. A large number of websites actively encourage sharing and reading stories.

With the help of several research assistants, my assistants and I searched the Web for any sites with stories about suffering. The selection of websites was limited to those that solicit stories related to pain or suffering. Thus, we excluded those sites with only a forum, where short comments and message exchanges are encouraged. We also eliminated sites catering to creative short story writing to

Table 2.1 Websites sampled for narratives of suffering

Websites with suffering narratives	Genres	Google links in 1,000s*
caringbridge.org	Bridging the suffering with friends	1,780
csn.cancer.org	Information and support groups	1,720
experienceproject.com	Life stories	8,860
goodtherapy.org	Faith, ethical therapy	70
helium.com	Writing feedback	52,100
lifestory.org	Life stories, faith	65,200
mayoclinic.org	Patient stories	3,729
mdjunction.com	Health information	1,020
somethingto share.com	Life stories, inspiration	2,220
save.org	Suicide-related stories, depression stories	2,120,000
suffering.net	Stories of pain, suffering, and faith	109,000
thereasons.ca	Suicide-related stories	245,000
voices.yahoo.com	Stories of suffering	112,000
whitewreath.com	Suicide-related stories	820
whypain.org	Stories of pain, affliction, and faith	118,000
Total		2,729,519

*‘Google links,’ in the rightmost column, is a measure of popularity or embeddedness within the Web. It is an estimate of the number of links to each of the above websites. It should be noted that this measure is limited, because some of the above websites have resources other than stories to which links may point

minimize the selection of inauthentic stories. Facebook has a “sufferings community” with 40,191 likes, and searching news sites yields many stories of suffering, but neither was included in this sample of sites. The sites we studied are listed in Table 2.1.

We randomly sampled stories, analyzing each in terms of its overall narrative and individual themes. Forty-five stories were analyzed, and the results are described and discussed within each of the eight frames of suffering.

Perhaps what stood out most was the raw pain and suffering described by the authors. In most website contexts, stories such as these received comments from others, and the original authors usually replied to acknowledge the comment. In a few instances, the comments told new stories that deserved mention.

Here is how one story, from the website *experience.com*, describes the agony of living with chronic pain. The writer, a young man in his 20 s, used the pseudonym ‘reallybored.’ While he did not give the source of his constant, piercing pain, he had been suffering for at least several months. He told his story in lyrical form, almost like rap music, which he explained: “I’m going out of my mind, the only thing I’ve got left is my ability to rhyme.” Elsewhere, he wrote:

I start to pour all my feelings out onto this page instead of punching my door; I’m on the verge of breaking. I can’t keep faking being all right when I don’t sleep at night.

He wrote that he had once been a musician, but could no longer play his guitar, which “felt like a knife.” Not surprisingly, his story received several comments, which he answered politely.

2.2.1 *Suffering as Punishment*

The first frame, *suffering as punishment*, is not a generally popular, modern way to express the experience of suffering. Only one story we found explicitly referred to suffering served as a kind of punishment. Even the victim of the suffering had mixed feelings about the validity of punishment as the essential meaning of his or her suffering. The story’s website was *save.org*, and the pseudonym ‘anonymous.’ Intense suffering began for this person 26 years before he or she wrote the story. Over these years, sleepless nights and turmoil continued despite a variety of treatments that included electroconvulsive therapy as well as numerous medications. The author did not share a specific diagnosis, but wrote of anxiety attacks and seven suicide attempts. At a younger age, a spouse, job, and apartment were lost. Religion seemed to have been both a source of comfort and internal struggles. At one point in the story, the victim said:

I believed for a while that God was punishing me for something done in my past. Others said I was selfish and said things like “Just pull yourself up and out of it” and “Stop feeling sorry for yourself,” which made me put myself down even more.

The story also gave evidence that this person used religious beliefs as a way to minimize suffering. The author wrote that “comfort was found in going to a safe place of worship,” even as friends admonished him or her for what must have looked like the author’s wallowing in pain. The storyteller’s concluding advice to others was: “Know that you are worth living and that God loves us all, no matter what you have heard or what society says.”

Even those who did not mention suffering as punishment may have attributed their pain and suffering to their past actions. The narratives we read were filled with family disruption, depression, social isolation, and so forth, all apparently direct consequences of the suffering. While these can be considered negative outcomes, they can also be conceptualized as components *of* suffering, but, as our objective was not to focus on causal consequences, that distinction was not explored in this analysis.

2.2.2 *Suffering as Reward*

The second frame, *suffering as reward*, consists of thinking about benefits gained from suffering. These might be small changes in one’s thoughts and values, like

increased gratitude, or they may be large shifts—some may believe withstanding pain and suffering is a desired religious experience.

Here is a story by Kattarrin on *experience.com*, written as an attempt to comfort ‘reallybored’. According to Kattarrin’s short story, she suffered from excruciating chronic pain and a seizure disorder that kept her from going out. If not for her daughter, she would not get out of bed. Still, she described suffering as a kind of reward:

Someday I might find someone who will benefit from my story and my pain, even if it is only to know that they too are not alone. I am here for you and I will pray for you. May the Higher Powers hear you and bless.

Not only did Kattarrin hint that personal benefit might result from her extreme pain and suffering, but she explicitly stated that her agony might benefit others. ‘Reallybored’ could now know that at least one other person cared. Her words of comfort were both complex and very personal. She believed that intimate sharing or co-suffering gave her struggle meaning.

What Kattarrin was talking about is what is often called the ‘all in the same boat’ effect, where people sharing common grief or enduring a painful disaster together feel a common bond. This may lead to long term cohesion among those suffering together, which might partially compensate for the agony felt by each individual.

Another story, this time by Shannon on *thereasons.ca*, illustrates how suffering from calamitous events can be transformed into a reward or benefit. Shannon and her new boyfriend Michael seemed very compatible and happy together. Because of that, she did not worry much when he told her about bouts of depression and drug use. They both had suicidal thoughts earlier in their lives, but that was all in the past.

After a wonderful Saturday evening date, however, he talked about fighting at home, but he promised her not to push his parents. The next morning, Michael’s sister called Shannon to say that he had committed suicide with a gun after an argument with his mother over what clothes to wear to church. Shannon was so devastated she wouldn’t eat for a week and had to be hospitalized.

When her boyfriend’s mother told Shannon that the last thing he held in his hand was a picture of Shannon, it was just enough to help her begin to restore her self-esteem. She explained it this way:

I know that I must pull through for all the ones that love me, including Michael. He will always have a place in my heart and I know no one can ever replace the way I felt about him, but it was his time to go and God is using this story to help other people and impact their lives.

Shannon began to recover from her deep sorrow and suffering when she knew Michael’s family had become aware of their dysfunctional role in his suffering. She grew closer to her friends and family, who became quite supportive, despite her initial phase of extreme withdrawal. People like Shannon, who are, for the first time, able to survive the death of a loved one or the agony of a painful illness, may ironically experience gratitude and a boost in self-esteem from having survived the tremendous emotional upheaval of a tragedy. They have come through something they previously could not envision tolerating.

2.2.3 *Suffering as Craving*

The frame for *suffering as craving* (or egocentric desire) is a popular attitude toward suffering in Eastern cultures. Equivalent notions of ‘addiction as evil’ and ‘sin as intoxicating pleasure’ are commonly held beliefs in most religious traditions. Buddhism teaches “Pain is inevitable; suffering is optional” and “the origin of suffering is craving,” and, in Western religions, suffering is sometimes said to result from indulging in ‘self-centered pursuits of the flesh.’ The implication is that exerting self-control over these immoral urges will free one from suffering.

Rick Derringer is an American rock star, having recorded 22 albums over past 35 years and performed with famous bands from the USA and Britain. He added a story to the website *lifestory.org*. In addition to listing his celebrity experiences, he admitted his addiction to alcohol and drugs. As he began to feel like his life was falling apart, he wrote, he remembered his Catholic upbringing and returned to the practice of prayer. His story states:

The Lord allowed me to survive drugs, alcohol and sins of the flesh so that I can stand here today as an example... The Lord can bless you with the strength to beat any addiction.

The implicit message here and in numerous other Christian testimonies is that human suffering is a direct consequence of cravings of the ‘flesh,’ a metaphor for self-absorption or attachment to anything that brings self-centered pleasure. It follows, in most religious teaching, that the way to escape from suffering is to stop one’s craving for egocentric or ‘sinful pleasures.’ The weakness of this point of view is that most people need more motivation than the possibility of vague suffering to give up things they and their friends think they enjoy. A more effective viewpoint is that alternative, other-centered pleasures offer deeper, long lasting forms of pleasure.

2.2.4 *Suffering from Sacrifice or Altruistic Actions*

This is sometimes called compassion fatigue or empathy fatigue. Stories about the suffering that results from compassionate action or empathic altruism tend to be scarce. Perhaps altruistic action is relatively rare. Another possibility is that people engage in prosocial or helping behavior, but do not think of it as altruistic or compassionate. More likely, people engage in altruistic actions, but only when it does not require a large sacrifice on their part. So, whether an act requires great self-sacrifice—enough to produce suffering—may depend on how much one values doing things for others. Extreme altruism will likely result in some degree of suffering on the part of the giver, but this is not the case for a great deal of caregiving.

The following story was found on *suffering.net*. A young boy’s older brother was severely injured in a car crash. He needed a blood transfusion, and his younger brother had the only blood type that matched. Their father asked the boy if he would be willing to give his blood so that his older brother could live.

Without hesitation, he agreed. Later, after a vial of his blood had been drawn by a nurse, the little boy turned to his father and asked:

Daddy, how long do I now have before I die?

One vial of blood would not kill him, but the boy did not know that. He believed his gift to his brother would mean giving up his own life, and yet he had not wavered. As stated in the New Testament (John 15:3), “Greater love has no one than this, that he lay down his life for his friends.” Rarely are we asked to sacrifice to this point of major suffering. Yet to end severe suffering around the globe may require most of us to sacrifice or suffer far more than we do now. This frame on suffering deserves thoughtful reflection by all.

Perhaps the most important conclusion is that genuine empathy and compassion do not demand that we suffer to the same degree as those suffering. They can be helped and their suffering relieved without actually experiencing the depth of their ‘unbearable’ suffering.

2.3 Suffering as Natural Destiny

Depending upon the time and place, much of the world’s suffering is caused by events of nature or random forces that we cannot control. Such destiny or fate is certainly true for natural disasters such as earthquakes. Other calamities such as floods, epidemics, famines and weather storms may be the consequence of both natural forces and human actions. We have few words in the English language that help us to think about the forces of nature that pain and suffering produce, but ‘destiny’ and ‘fate’ are two. Pain and misery are inevitable; taking undue blame for them is not and should be avoided whenever possible. Likewise, we should not blame fate for disasters produced by human behaviors. Therefore, it is important to learn more about natural disasters so that we can distinguish ‘acts of God’ from events resulting from technology or other human creations. By allocating blame correctly, we can engage in actions that will alleviate or perhaps avoid more human misery than already exists.

Brandi, on *stories.yahoo.com*, wrote a vivid description of her first miscarriage. She had had one successful child birth, but this was totally different. The ordeal of severe pain and unsuccessful trips to the hospital continued for several weeks. When she finally miscarried at nearly seven weeks of pregnancy, the pain was excruciating and the grief overpowering. Three more miscarriages followed during the next year. With each new miscarriage, her pain and suffering continued. Eventually, Brandi came to peace with the repetitive ordeal. This is how Brandi explained it:

I now know that most miscarriages are due to something being wrong with the baby and miscarriage is nature’s way of letting only the strong survive.

Coming to believe that miscarriages are “nature’s way” of eliminating embryos with genetic problems was eye-opening for Brandi, making it much easier to

accept her pain and cope with her grief. Something as simple as learning the scientific facts behind suffering, or seeing more clearly the role of destiny, can greatly reduce needless suffering.

2.4 Suffering as Pain Management

The most frequent narratives on the management of pain and suffering were off-handed comments about the inadequacy of the authors' pain medications. Quite a number of the online writers referred to their pain meds as a joke; they helped, sure, but the help was tiny compared to the pain remaining.

As expected, those suffering from cancer were especially unhappy with their medications. They talked about their chemo meds as making them sick, but felt they had no choice but to take them. Several even referred to their medications as dangerous, perhaps because the patients' were sometimes left with severe pain but also because taking the medications often produced new, unpleasant side effects.

A third common theme was the stigma that came with taking potentially habit-forming drugs for pain. A woman with the pseudonym 'actvforlife' at *experienceproject.com* wrote of severe and constant neck and back pain stemming from a whiplash injury in an auto-truck crash. After 6 years, she on medication, and while it helped, it made her feel alienated:

I am on pain meds, which are a stigma for me from my family.

Medications are not the only tools for pain management. Hypnosis and alternative medicine techniques including dietary adjustments may help manage pain. One strategy some of the story writers shared was improved self-compassion (although this is my interpretation). Neff (2011), a leader in the self-compassion movement, defines self-compassion as embracing one's pain, feeling unconditional self-kindness, and avoiding destructive patterns of fear, negativity, and isolation. Research on the effectiveness of self-compassion training confirms its effectiveness in the management of pain and suffering (Neff 2011). Although pain management is generally associated with prescription drugs and medical procedures, there are spiritual practices like meditation, and self-compassion (as opposed to self-pity) exercises that should be included among the tools for the management of pain.

2.4.1 Relief of Suffering as Human Purpose

Mayerfeld (1999) persuasively argues that the reduction of suffering is morally more important than the promotion of happiness and that "most of us greatly underestimate the force of the duty to prevent suffering." There are numerous ways to work toward the relief of suffering, ranging from caregiving for a family member (perhaps a sick child or an aging parent) to becoming a full time

disaster relief worker. Such dedication benefits not only the victims of the suffering, but also the reliever of that suffering—more commonly called the caregiver. Caregiving benefits the caregiver primarily by providing a highly compelling purpose or meaning for living. This meaning often is reinforced by the gratitude of those whose suffering is abated.

The experiences of suffering persons and caregivers have been investigated extensively among those who volunteer as within-family caregivers. Some of the findings from this research, both quantitative and qualitative, are mentioned here because they illustrate the benefits and costs that come to those who work toward the reduction of suffering.

The American Cancer Society estimates that three out of four families have at least one member who is a cancer survivor. Their National Quality of Life Survey for Caregivers began in 2002, when 1,635 cancer caregivers were surveyed. The study followed up in 2005 and 2008. Many, but not all, caregivers reported their cancer caregiving experience as having given them new perspectives and added meaning in their lives.

Based on this study, Kim et al. (2007) concluded that multiple personal pathways helped caregivers “find meaning in their caregiving role.” The study showed that caregivers who found meaning in the experience developed greater satisfaction with life and experienced fewer episodes of depression. These results were confirmed in a European study by Minaya et al. (2012).

In another study (not limited to cancer care), the Washington State Personal Family Caregiver Survey discovered that many family caregivers find deep satisfaction and meaning in their role, but it often comes at substantial cost to the caregiver’s own physical and mental well-being. Researchers Montgomery et al. (2007) concluded that, while some caregivers derived greater meaning from their lives as caregivers, they also struggled with identity change, as did all long-term family caregivers.

Noonan et al. (1996) interviewed 48 informal caregivers to the elderly, and the narratives they reported support others’ claims about the importance of meanings and the quality of life in understanding suffering. They found that predominant caregiving mentioned included gratification and satisfaction, family responsibility and reciprocity, and friendship and company.

Here are some illustrative quotes:

My aim is to make the quality of her life, what she has left, as nice as it can be.

Mother is happier than she’s ever been in her life, which makes me very happy.

I’m doing the best I can and am glad to do it... It is a labor of love.

Finally, while the authors of our collection of web stories were not caregivers themselves, many expressed a hope that others learn from their experiences of agony and misery. Sabrina, who left a story on *whitewreath.com*, is a good example. After struggling for years with suicide attempts, she recovered and now provides help for others with online comments and suggestions. One such suggestion was:

One day you will realize that you don’t have to hide, you will realize you are much stronger than you ever gave yourself credit for being.

Those who have experienced the agony of suffering themselves and put it behind them (or, at least, have come to manage it better) tend to feel empathy for those suffering in similar ways. Empathy does not make one a therapist, of course, but these people may be able to inspire and support others in proactive approaches to their challenges.

2.4.2 Relief of Social Suffering as Progress in Quality of Life

As we found no web stories related to this frame of suffering in the 15 websites of our main source of narrative data, special searches were made for stories about humanitarian aid and relief workers and the meaning of their work. The principal conclusion of this extensive search was that humanitarian aid and relief workers almost never write about their own motivations for reducing suffering. Perhaps they have been neglected as a professional group because the organizations for which they work put their time and attention toward the huge and horrendous plight of their clientele, the suffering victims of various calamities. This may leave relief workers less likely to write about their own comparatively ‘unremarkable’ experiences.

It goes without saying, though, that reducing or eliminating the suffering of victims of tragic disasters improves the victims’ quality of life, to the extent that they make contact with humanitarian aid of some kind. How quickly and extensively their quality of life improves depends largely upon the funding support and organizational effectiveness of humanitarian aid and relief programs. A large part of program effectiveness is the human capital represented by humanitarian relief professionals, so it is surprising that so little is known about them.

One major exception is a book (Bergman 2009) that contains a large collection of stories by aid and relief workers. These stories give us glimpses into workers’ motivations and the meanings of their work supports their lives. In the introduction, Bergman wrote:

Humanitarian workers, in general, have a different notion of home and security. They often complain, jokingly, of the pressures of a “normal” life and admit to enjoying, or needing, the adrenaline rush of the front lines.

One of his stories is exemplary:

I continue working. I do this type of work because I believe in what we are trying to achieve and experience a tremendous sense of satisfaction when I help people. I see severely malnourished children on one trip, and when I return a month later, they are running around and smiling. (p. 132)

Another story Bergman (2009) included is by a Vietnamese woman who worked as an aid worker. In the era after the Vietnam War, while flying over the country, she observed:

No longer suffering from war, they’re suffering from a different kind of struggle—fleeing from poverty and natural disasters. (p. 39)

Her comment points out how the social suffering of a peaceful era may be as devastating as civil war. If not won, the war on poverty and environmental preservation can lead to as much destruction of human life as a major, modern war from which an estimated four million people died.

Another perspective on the meaning of aid work to an aid-worker is summed up in a quote from a long eBook written by Peter (2007) about his life as an aid worker:

This could have been my family, my life. But destiny has put them there and me here. Sheer luck determined those who suffer and those who never realize how lucky they are. Sheer destiny determined those who need help and those that can help. I can help. And that is why I am an aid worker.

Reduction of suffering is what makes life most meaningful for someone devoted to humanitarian action. But reduction of suffering is not enough. All people must also work to reduce social suffering, finding and eradicating the root causes of poverty, violence, and other social forces that fuel greater and greater suffering.

2.5 Conclusions

The culture of the Web provides for the emergence of an online genre of short storytelling that magnifies drama. Gripping stories may capture the attention of readers who have had similar experiences or who can empathize with the author's suffering. The typical story exudes deeply felt, negative emotions associated with traumas such as a bout of depression, a suicide attempt, a late-stage abortion, major illness, or pain due to accident-induced muscle damage.

One of the most common sources of suffering in Web stories is depression, usually clinically diagnosed. The suffering we read about ranged in length from a few weeks to 75 years of depressive episodes. The most extreme depression in the Web stories was that of someone who lived with bipolar disorder over a period of years, including physical and mental pain and attempts at suicide. The author's words paint a portrait of a life that feels like war-time torture.

Another qualitatively different type of story is that of a mother grieving for the loss of her son to suicide. Though he had been diagnosed with schizophrenia and depression, she still seemed to shoulder some of the blame for his death. Though a relatively mild instance of suffering, she admitted that the episode degraded her quality of life because now she is "basically scared of everything."

While some suffering arises from a shared calamity, the Web stories of suffering were typically about personal trauma. Parallel suffering, such as commonly experienced after a major earthquake, tends to provide a natural social support system. Alexander's (2012) analysis of social traumas reveals how unbelievably tragic and horror-filled many stories of cultural trauma end.

In the Web stories, the victims' family and other support systems sometimes failed to provide adequate care and comfort. Chapman and Volinn (2005), in their study of chronic back pain, found that victims often experienced serious problems

with family disruption. Some of this arose around the sufferer's inability to work and provide their former level of income.

Other problems arose because family members experienced ambiguous loss (Boss 1999; Mulvany 2010). Such loss arises when it is difficult to predict if (and when) the victim might return to their former participation in family relationships. Role reversals, changed roles, and withdrawal from family activities can all threaten the cohesion and viability of family and individual relationships.

References

- Alexander, J. C. (2012). *Trauma: A social theory*. Cambridge: Polity Press.
- Bergman, C. (2009). *Another day in paradise: International humanitarian workers tell their stories*. Eugene: Wipf & Stock.
- Boss, P. (1999). *Ambiguous loss*. Cambridge: Harvard University Press.
- Chapman, C. R., & Volinn, E. (2005). Narrative as a window on chronic disabling back pain. In D. B. Carr, J. Loeser, & D. B. Morris (Eds.), *Narrative, pain, and suffering* (pp. 73–86). Seattle: International Association for the Study of Pain Press.
- Charon, R. (2005). A narrative medicine for pain. In J. Carr, D. Loeser, & D. B. Morris (Eds.), *Narrative, pain and suffering* (pp. 45–53). Seattle: International Association for the Study of Pain Press.
- Illouz, E. (2003). *Oprah winfrey and the glamour of misery*. New York: Columbia University Press.
- Kim, Y., Schulz, R., & Carver, C. S. (2007). Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine*, 69, 283–291.
- Minaya, P., Baumstarck, K., Berbis, J., et al. (2012). The CareGiver oncology quality of life questionnaire (CarGOQoL): Development and validation of an instrument to measure the quality of life of the caregivers of patients with cancer. *European Journal of Cancer*, 48(6), 904–911.
- Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family Caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.), *Handbook of gerontology: Evidence-based approaches to theory, practice, and policy*. New York: Wiley.
- Mulvany, A. P. (2010). *Flood of memories: Narratives of flood and loss in Tamil South India*. Publicly accessible Penn Dissertations. Paper 383. <http://repository.upenn.edu/edissertations/383>. Accessed 18 May 2013.
- Neff, K. (2011). *Self-compassion: Stop beating yourself up and leave insecurity behind*. New York: HarperCollins.
- Niv, D. (2005). The chronic pain narrative and quality of life. In D. B. Carr, J. D. Loeser, & D. B. Morris (Eds.), *Narrative, pain, and suffering* (pp. 53–72). Seattle: International Association for the Study of Pain Press.
- Noonan, A. E., Tennstedt, S. L., & Reblsky, F. G. (1996). Making the best of it: Themes of meaning among informal caregivers to elderly. *Journal of Aging Studies*, 10(4), 313–327.
- Peter, (2007). Why I am a humanitarian aid worker. In eBook, *The road to the horizon*. <http://www.theroadtothehorizon.org/2009/03/why-i-am-humanitarian-aid-worker.html>. Accessed 13 Feb 2013. Note: the author identifies only as 'Peter'.
- Sennett, R. (2000). *The corrosion of character: The personal consequences of work in the new capitalism*. New York: W. W. Norton.



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