

## Painful Lessons

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**Abstract:** A larger and extremely central portion of individuals' experiences involve those that result from injury, illness, hospitalization, and pain. The current story describes some of the aspects involved in injuries and hospitalization based on my personal experience as a burn patient. Each of the descriptive parts is accompanied by a section that interprets the experiences, places them in a broader context, and proposes directions for future investigations.

## Painful Lessons

*It was a large, full-size mirror. I got closer and closer and finally turned and looked at myself. Legs bent and thickly covered in bandages; back completely bent forward; arms collapsed sideways and bandaged. My whole body was twisted and looked foreign and detached from what I felt was me. Still, the worst was my face. The whole right side was open flesh, yellow and red with all kind of pieces of flesh and skin hanging from it. It looked as if it was made out of colorful wax and it was in the process of melting. Eyes were pulled severely to the side. The right side of my mouth, ear, and my nose were charred and distorted.*

*It was hard to grasp the details. I just stood there and tried to take in the whole new me. Was the old me still there in the image that looked at me from the mirror? The only thing I could recognize was my left eye gazing at me from the mirror – placed in this different and foreign body that didn't look anything like me. During the treatments I saw parts of my body so I knew how some of the scars looked like. I was also told that the right side of my face was badly burned but, somehow, until this moment the connection was not real. I wanted to stay and stare at myself and yet I wanted to turn away and not look any more. Soon enough the pain in my legs made the decision for me and I went back to my room. Was this really me? It was, yet it was hard to see, believe. Or accept that this was the new me.*

The following story describes in some detail my experiences as a burn patient. On what would have otherwise have been a normal Friday afternoon, my life changed irreversibly in a matter of a few seconds. In an instant, my future hopes and dreams slipped away, to be replaced by a long struggle toward recovery. On that day, an explosion left me with 70 percent of my

body covered with third degree burns. These mere few seconds that forever changed my life marked the starting point of a long and painful period of hospitalization. For the three years that were to follow, I faced not only, hospitalization and pain but emotional turbulence as well.

Burns and their treatments cause extreme pain over a long period of time – creating pain that is more intense and longer lasting than almost any other medical condition. In what follows, I will describe some of these experiences in order to shed some light on patients’ experiences of extremely painful episodes. After describing each aspect of my experience, I will attempt to provide a short analysis of the experience, focusing on related research questions, and on implications for policies regarding the treatments of patients. The style used for the exposition relies on indented italic text to describe a set of experiences (taken mostly from my diary), and regular text in interpreting and discussing these experiences.



## The Injury

*The explosion came from out of nowhere. Flames surround me. I couldn't see through the glowing white light of burning magnesium. Instinctively, I back away from the flames. Smoke permeating the room and although I can hardly see, I noticed that my T-shirt has caught fire. As if in a dream, I used my hands to put it out. Time slows down. I am thinking what to do next. Someone calling from the other side of the room is trying to guide me toward an exit. Realizing I am trapped, the flames bursting between the door and me, I decided to run through the fire in order to escape. When I reach the other side, my clothes once again in flames. I remove my shoes, what remain of my T-shirt, and my trousers – all still burning – and make my way to the exit. There, standing in partially charred socks and underwear, I drop down to the safety of the cold stone floor and look down at my hands. The right one is black, but it still has the shape of a hand with which I am familiar, and thus it seem generally fine. But, my left hand had large pieces of skin hanging loosely from it, as white as the stone floor beneath me, with particles of chemicals and ash showing clearly against the white skin. Only then does the unbearable pain in my arms and legs overcome me. Trying to minimize my pain, I moved as little as possible and breathed small breaths. Soon the medical team arrives and carries me away.*

**Detachment:** Initially, the entire experience seemed disconnected from reality. It was as if I were partaking in a movie scene, observing my own behavior, but not experiencing it as an active participant. During these detached moments, subjective time passed slowly and each decision seems to have been weighted and examined deliberately and carefully. It felt as if I had

plenty of time to decide how to put the flames out, what part of the flames to distinguish first, and where to escape to. A second aspect that made the experience seem less real was the low level of pain during these initial moments. Without much difficulty, I was able to put out the flames with my hands and run through the fire to safety before the onset of any debilitating symptoms. The fact that I was able to flee the building and walk to the front of it becomes an even stranger phenomenon when one realizes that it took me several months of rehabilitation before I was able to walk this distance again.

One important question that arises concerns the nature of the “slow motion” perception and that of the observer/actor separation. Based on their co-occurrence, it can be argued that the same underlying mechanism might have caused these two phenomena. Digestion of information can be difficult when individuals are subjected to experiences that are highly unexpected and where there are no scripts for their progression. Processing difficulty in turn can create the subjective feeling of “slow motion,” while simultaneously making it difficult to interpret the information as being self-relevant, creating the actor/observer discrepancy that I felt during these moments.

**Ability:** Once outside the building and away from the initial danger, my physical and psychological reactions to the injury changed. My strength gave way and I was lying motionless waiting for help to arrive. Additionally, once away from the explosion, I recognized and succumbed to the pain, trying to limit my motion as much as possible to reduce the pain. How is it that the pain had not been felt earlier and was noticed only after I had gotten away from danger? Early work by Beecher (1946) suggests that the experience of pain is regulated by

situational determinants influencing the experience of pain after an injury. Beecher compared reports of pain and requests for pain-relievers from battlefield and car injuries of similar magnitudes. The results showed that pain was consistently reported as less aversive, and that the requests for painkillers were lower, following battlefield injuries compared with car accidents. Beecher attributed these results to the “happiness” soldiers felt about escaping the dangers of the front lines. The victims of car accidents did not have this benefit of relief, this “happiness factor,” to spur them on, and thus felt pain more immediately.

A different interpretation of Beecher’s results could be based on the functional role of pain. From this perspective, we can examine changes in pain thresholds by identifying the functional role of pain for the person experiencing it. Immediate pain can be useful because it prevents an organism from harming itself further. Delayed pain, as in the description above, can allow the organism to function long enough to remove itself from harm’s way. The combined functions of immediate and delayed pain can have different implications for different causes of injury. In Beecher’s analysis of battlefield injuries vs. car injuries, it becomes obvious that it would greatly benefit a soldier to evade pain until he has removed himself from further danger. In most car accidents, however, fleeing the scene is not as necessary and could likely cause unneeded stress on the injuries. A compelling question concerns the mechanism allowing an organism to differentiate between these cases, enabling it to act accordingly.

## First Days at the Burn Center

*Once in the burn unit, I have my first meeting with the “bath,” an integral part of my life to be. From then on I am given a bath every day, with the exception of the days I am operated on (which made the operations much more attractive).*

*The intensity of the pain caused by the bath shocks me each time. It is an intensity beyond the ability of my day-to-day memory to record and comprehend, and it always proves worse than my expectations. The bath water is purple from iodine and the burning sensation begins the moment the metal forklift lowers my stretcher into the large metal tub. As soon as I am properly soaked, the nurses began removing the bandages. In the absence of skin, the bandages are stuck to raw bleeding flesh and their removal is long and painful. The nurses usually start with my legs and proceeded to my arms, chest, and finally the most painful of all, my neck and face. Throughout the removal process, the nurses and I negotiate frequently about the speed of the treatment and about breaks we take to make the process less horrific. The speed at which the nurses remove the bandages is almost always too fast for me. They hold on to the edge of a bandage and quickly strip it off. This method causes me a short, but intense pain as the bandage is removed, followed by a longer and more muffled pain. This pattern is repeated for each of the many bandages up and down my body. In addition to wanting to slow the removal process, I also want to break up the treatment and take a few short periods to calm down. The nurses and physicians are generally opposed both of these suggestions. They argue that finishing the bath as fast as possible is the best approach for me. When the process finally ends the stretcher is lifted out of the tub and a layer of Siverol (a treatment for*

*burns) is applied to all my exposed areas, which was about 70% of my body. New bandages are applied, I then return to my room for physiotherapy and other arduous treatments, while the time is clicking until the procedure is repeated again the next day.*

**Patterns of pain over time:** Regrettably, delivering experiences of intense pain to patients is a common and necessary component of many treatments. While the treatments themselves and the pain that accompanies them are, in many cases, unavoidable, it may be possible to deliver the same treatment while reducing the overall experience and memory of pain. During the past decade, it has become clear that the overall pain of an episode (a sequence) does not equal the sum of the momentary intensities (for reviews of this research, see Ariely and Carmon 2000; Huber et al. 1997; Frederickson 2000; Kahneman 2000). Research in this area has revealed that the overall pain of prolonged experiences is largely influenced by the final intensity of the experience (cf., Frederickson and Kahneman 1993; Kahneman, Frederickson, Schreiber, and Redelmeier 1993; Redelmeier and Kahneman 1996; Varey and Kahneman 1992) and its rate of change (Ariely 1998; Hsee and Abelson 1991; Hsee, Salovey, and Abelson 1994; Lowenstein and Prelec 1993). In other words, pain that worsens over time is perceived to be more painful than pain that improves, or one that remains at the same level. Based on this work, and putting aside for now, the questions of whether intensity is most influenced by the final state or by the slope (direction and rate of change in pain intensity over time), it may be that the optimal way to deliver treatments to patients might be to initially deliver the most painful part and then move on to less painful aspects.

**Breaking up treatments:** A second issue that arises from the description of the bath



procedure concerns the question as to whether breaks during the bath treatments would have been more desirable. Would it benefit a patient in this situation to take short breaks? Or were the nurses right in delivering the treatments in one prolonged session? Initial evidence (Ariely and Zauberan 2000) suggests that the answer to this question, at least partially, depends on whether the breaks moderated the pattern of the pain. Based on their findings, Ariely and Zauberan propose that in cases where the sequence of pain becomes more painful over time, breaks seem to be helpful in reducing the overall retrospective evaluations, whereas in cases where the sequence of pain becomes less painful over time, a single session without breaks seems to reduce overall pain.

When contemplating introducing breaks, we can think about short breaks to catch one's breath or long breaks that allow for more substantial recovery. Would the level of pain experienced differ if the treatment had been split into multiple sessions with longer breaks (i.e., morning and afternoon/evening), allowing for a longer period of rest between each component? One consideration related to taking breaks during treatment is the patient's ability to cope with the inflicted pain. For example, if coping energy is "used up" (Baumeister, Muraven, and Tice 2000; Linville and Fischer 1991) during painful treatments, it is important to understand how coping ability is renewed. For example, if coping ability is renewed only overnight, any breaks throughout the day will not significantly alter patients' ability to endure treatment. On the other hand, if coping ability has a relatively short regeneration period, multiple and frequent breaks would indeed be beneficial. The precise nature of coping energy may be more complex, as it is likely depends on the individual patient and the specific treatment required. For example, it could be that fear of the next treatment session could inhibit coping recovery. If this is so, a

better understanding of the individual and the exact treatments will be needed to design a treatment plan, whether broken up or concentrated.

**Duration of treatments:** A separate recommendation that emerges from the work on hedonic calculus is that when delivering treatments, it may be desirable to reduce intensity in favor of prolonged durations. After all, if individuals pay attention mostly to a few key features of the ongoing experience (maximum intensity, end intensity, rate of change), the effect of duration might very well be underweighted and thus have a lower impact on the experience. For example, it is possible that doubling the duration of a given experience (e.g. repeating it twice) might be perceived as less than doubly painful.

However, recent work (Ariely, Kahneman, and Loewenstein 2000; Ariely and Loewenstein 2000) suggests that the role of duration in overall evaluations might be more difficult to ascertain and largely influenced by the judgment context (e.g., repeated vs. unique experiences, the goal of the judgment, and the amount of change over time). Thus, before recommendations about the effect of treatment duration can be made, more research is needed concerning the integration of duration in overall evaluations. It should also be noted that all the work on retrospective evaluations of experiences has largely focused on immediate evaluation (immediately once the experience has ended). Whether delayed time perspectives point to the same integration rules is an open and important question.

**Control:** The very word “patient” implies, somewhat ironically, that one must endure treatments, varying levels of pain and discomfort, and the passage of time passively and

patiently. This implied passivity raises questions of controlling one's environment, lack of control, and their implications. Is the level of control a patient feels directly related to his or her fear of treatment and the perception of pain? Research on learned helplessness has convincingly demonstrated that when pain is predictable or under the control of the organism, it is perceived as being less aversive (Herberman 1992) and even as causing less damage to the natural immune system (Sacerdote et al. 1994; Sieber et al. 1992; Thompson and Collins 1995).

In my case, there were two particularly memorable nurses. One allowed me to have breaks and even, from time to time, remove some of my own bandages, while the other (the only male nurse in the department) gave me no control over the treatment process. My appreciation and memories of these two nurses are vastly different. The influence of the nurses on my well-being started hours before the bath treatment, once I learned who was going to be the nurse on duty for my bath. In good days, when the nurse that gave some level of control over my treatment was in charge, the level of dread and fear that preceded the bath were reduced substantially and so was the perception of pain during the treatment itself. The nurse who gave me no control caused me to feel an intense anxiety that increased as the time to the treatment was approaching and it was also exacerbated throughout the hospitalization period. The difference that these two nurses had on me was so large that I tried to learn the nurses' shift schedules and arrange conflicting treatments during the times the "no-control nurse" was on duty or to arrange for other nurses to treat me before the tyrant could "get me."

**Years later:** As an aside, I should explain that my curiosity about hedonic calculus (combination of pleasure and pain over time) evolved as a result of my hospitalization and the

various disagreements I had with the physicians, nurses, and their perceptions of my “best interests.” Years later, after gathering my first round of experimental evidence (aimed at understanding the value of the short-fast treatment used most routinely), I returned to the burn department and presented my results. At the end of my presentation, one of the nurses pointed out a logical flaw in my argument: I was assuming the goal should be to minimize the overall pain of the patient. I was neglecting the caregiver’s emotional difficulty in delivering treatments to patients who were screaming and begging for them to stop. Since the nurses experience the duration more readily than the pain intensity, and since the treatment’s duration was under their control, to reduce the nurses’ pain, the short-fast treatment was chosen.

### **First Operation**

*Midmorning, one of my physicians enters my room accompanied by two nurses. He informs me that my right arm was so swollen that the pressure is preventing blood flow to my hand. They neatly arrange before me a tray of what seems to be dozens of scalpels and explain that in order to reduce the pressure, they have to cut through the skin to drain the liquid and reduce inflammation. I cannot help but think of the ancient British barbers that used to bleed patients as a form of medical treatment. The physician also informs me that since my heart and lungs are not functioning very well, they will have to perform the operation while I am in my hospital bed and without anesthesia. This frightens me to no end. In an attempt to comfort me, the physicians informs me that since most of the nerves in my right arm are dead, I should not experience much pain – but he is not very convincing, and, in fact, turns out to be so very wrong.*

*One of the nurses holds my left arm, the other my right. I watch as the knife advance slowly along my arm, creating the sensation of a deep tear. I can see the physician cutting me with this sharp scalpel, but I feel as if he were tearing me open with a garden tool. The intensity of the pain catches me by surprise and leaves me gasping. It is unbelievable, unlike any pain I could have imagined. It begins at my elbow and advances slowly until it stops near my wrist. Then it comes again, a second time, starting at my elbow and moving upward. I scream and begged them to stop, "You are killing me,!" I cry out. No matter what I say, not matter how much I beg, they do not stop. The pain grows stronger. "Stop!," I scream out over and over again. I tell them I cannot stand it any longer, but they only hold me tighter. Finally, the physician tells me that he is almost finished and that the rest will pass quickly. He tells me to count to 10 and that when I reach 10 it will be over. I start counting as slowly as I could bear. 1, 2, 3... Time seems to slow down. The pain captures every aspect of my being. All I have is the slow counting. 4, 5, 6... The pain moves up and down my arm as a new incision was made. 7, 8, 9... I still remember the tearing flesh, the excruciating anguish, and the waiting... as long as I could... before yelling... TEN!*

*They stop. I feel like an ancient warrior confronting his suffering with brave nobility. I also feel exhausted. "Very good," the physician congratulates me. "I have made four incisions in your arm, from shoulder to wrist; now we just have a few more seconds and it will REALLY be over." My imagined brave warrior dissolves into a patient defeated. The pain, which a few seconds earlier had seemed manageable, is once again perceived with full-blown terror. "Please, I will do anything, just stop," I beg. The repeated*

*cutting terrifies me. I put all my energy into convincing myself to hold on to as long as possible, certain that the 10-count would bring the end. How could I bear this again now? Fortunately, or unfortunately, I had no say in the matter. This time they hold me even tighter. "Wait, wait," I said, but the doctor proceeds silently with his cutting. When the arm is "finished," he makes two cuts in each of my fingers. My hand is extremely sensitive and the pain seems unending. I am helpless. I have no ability to control myself and begin to cry. I scream, cry, and shout all at once. I can't recall at all the length of the procedure, but I remember counting... the numbers, and shouting when I reached 10, knowing that it still wouldn't be over. Finally it is over. Bleeding and crying, I am left to rest.*

*At the time, I didn't understand the importance of this operation. A few months later, I find out that some of the physicians wanted to amputate my arm and that the surgeon who had operated on me wanted to try to save it- despite popular opinion. By saving my arm, he caused me great suffering, both that day and for years to follow. I have often wondered as I was having other surgeries on that arm if he had made the right decision. As years pass, however, still with little function in my right hand and with daily pain, I do thank him and know he made the right decision for me.*

**Effects of knowing the end of an experience:** Based on this account, I would like to suggest that counting to a known target, and having the "knowledge" that once a target has been reached the pain will end, is likely to help patients manage their own coping abilities- reducing their overall pain and prolonging the period of time a treatment can be sustained. In addition,

knowledge of an end point can also increase the feeling of control as well as decrease levels of fear and dread, all of which can lead to the same beneficial outcomes.

Even casual observations of people who exercise suggest that knowing where one is in relation to their goal, and being able to assess how much effort is required to reach the end, can help sustain motivation and increase the probability of achieving the goal. In a small test of this concept, I asked 60 gym-goers to hold, using their dominant arm, a 5 lb. weight, stretching their arm to the side of their body parallel to the ground, for as long as they could. Each duration was recorded and termed  $X_i$ . Participants were next asked to repeat the process using their other (non-dominant) arm for the duration of  $X_i + 30$  (thirty seconds longer than they had been able to hold the weight using their stronger arm). In this second trial, respondents were randomly assigned to one of three counting procedures. In the “up-counting” condition, the experimenter counted each second aloud from 1 until the time goal ( $X_i + 30$ ) or until the respondent stopped of his/her own accord. In the “down-counting” condition, the experimenter counted the seconds aloud from  $X_i + 30$  down to 0 or until the respondent stopped of his/her own accord. In the “no-counting” condition, the experimenter provided a free association every second, preventing the participants from knowing where they were in relation to the goal.

The results show that the different counting conditions greatly influenced the length of time respondents were able to hold the weight in the non-dominant arm [ $F(2,57) = 43.48, p < 0.001$ ; all the pair-wise differences  $p < 0.001$ ]. Participants in the down-counting condition managed to hold the weight for the longest time (24.7 seconds more than in their dominant arm and 5.3 seconds less than the requested endpoint). Participants in the up-counting condition managed to

hold the weight for a shorter time (5 seconds more than in their dominant arm and 25 seconds less than the requested endpoint). And participants in the no-counting condition held the weight for the least time, and, in fact this was the only group in which the non-dominant arm was held for less time than the dominant arm (22.6 seconds less than in their dominant arm and 52.6 seconds less than the requested endpoint). Note that only two of the respondents reached their target, and the results hold in the same way if these two respondents are eliminated from the analysis, indicating that it is not simply having a known endpoint that causes people to reach their goal. In sum, these results clearly show that knowledge of the end (comparing the upcoming and down-counting conditions to the no-counting condition) increases tolerance. The results also show that having a more clear view of an endpoint (the 0 in the down-counting condition compared with the  $X_i + 30$  in the up-counting condition) increases tolerance even further.

Several questions arise from these findings. Why does knowledge of the endpoint improve coping ability and motivation? What tools can we provide patients to better cope with pain and thereby diminish it? Does the improved coping ability (caused by knowing when the end will arrive) hold for all timeframes, and is this knowledge as beneficial for various time periods, e.g., six months, one week, eight hours, 30 minutes, three minutes? Moreover, once the endpoint has been identified, do the benefits of knowing it increase as time passes and the end draws nearer? More research on the psychological effects of “end-knowledge” regarding endurance and coping ability is needed.



## Memory of Pain

*As I write these lines, I am trying to recall the pain I experienced during my hospitalization. The pain itself, I cannot remember. I am left with only the memory of its intensity and the emotions that these memories invoke. I remember the scalpel cutting through my arm and hand. I remember the pain during my daily baths, the pain of physical therapy, of getting out of bed for the first time. Yet, these memories are substantially different from the pain itself. Even the pain I still experience is not the same. Nothing in my memory or experience provides me with strong clues of the pain I felt during my hospitalization.*

*Although I can't remember the exact pain I had during these years, I am not completely detached from the adversity it brought into my life. When I return for visits to the burn department, when I smell one of the many smells from that period of my life, or even while writing these recollections now, my state of consciousness changes. There is clearly sadness during these experiences, but beyond these emotions, there is also a feeling of physical discomfort. I become nauseated, uneasy, my throat dries out. It is hard to fully describe, but somehow my body remembers the emotional residues from that time, replaying them for me. The same physical changes also help me to bring the events of the past more clearly to mind.*

*In addition to the pain, I experienced other emotions during my three years in the hospital. Some of these memories, such as helplessness, hopelessness, and fear, are even less vivid than my memory of the actual physical pain. I recall having these intense*

*emotions on a daily basis, but aside from recalling that I had had them, they left no memory trace for me to feel or reconstruct. The cognition of knowing I have experienced these emotions is present, but without any emotional intensity, it is abstract and amorphous. In contrast, I vividly remember “social emotions” – emotions that were caused by my interactions or fear of interactions with others. I still recall the emotions I experienced when I first looked at myself in the mirror after being burned, those I experienced when I left the hospital for the first time and saw my reflection in the eyes of strangers around me, and my reaction to the people who shook my hand.*

These accounts suggest that there might be differences in the memory processes for emotions such as fear and pain, and social-emotions. Most notably, memories for social emotions seem to be long lasting relative to the memories for pain and other emotions. Perhaps because social emotions are based on the reflection of one’s own image in the eyes of others, it is that these emotions require more elaborations (and more effort) in terms of the self to be experienced, and are thus remembered with more clarity. In other words, it may be that the cognitive effort required to experience these emotions is what makes them more memorable. If this is the case, other emotions that are cognitively elaborated upon at the time they are experienced might also be remembered more vividly. A different account for the differences between the memory for emotions and social emotions might be the frequency with which they occur. During my hospitalization, pain, fear, and hopelessness were frequent and recurring emotions, while the social emotions were experiences with much lower frequency. It is possible that it is the rarity and uniqueness of these emotions that makes these memories more salient in retrospect.

In addition to the differences between social and other emotions, it is possible that memory for physical pain is distinct from memory for other emotions such as fear and hopelessness. While memory for such emotions is not available years after these experiences, memory for pain seems to have deep rooted traces that can be invoked by thinking about the experiences or by encountering memory cues such as smells or sights.

Difference in memory for the various types of emotions and experiences (physical experiences, emotions, and social emotions) might provide a clue as to the dimensionality of emotions, both in how they are experienced and in how they are remembered. Finally, it is important to note that declared memory might be disassociated from implicit memory. It is possible that although the explicit memory for some emotional dimensions are low or even non-existent, their effects on behavior can be substantial and long lasting.

### **Long-Term View**

*The injury took place many years ago, and as time goes by, more of my life has been spent in this physical state. In retrospect, I try from time-to-time to take stock of this experience and account for the good and the bad, weighing my life against how it could have been. I am not foolish enough to convince myself that I am better off for having this injury, but I do allow myself to see a few advantages in this fundamental change of my life. The long-term changes caused by the injury-related experiences include changes to my personality, the ways I view myself, the ways I view others, my motivation, my interests, and my reaction to physical pain.*

*Personality-wise, this experience has given me a more relaxed perspective on many aspects of life – knowing how horrible life can be, makes the small daily problems I encounter seem less important, if not altogether meaningless. Consequently, I find it difficult to worry about setbacks and mishaps in my professional and personal life. A somewhat less endearing consequence of this casual approach to life is that empathizing with others became more difficult. As I am not very concerned with my personal “small problems,” I also can’t get too excited about the “small problems” others are experiencing.*

*Because a large part of my injury is physically observable, one aspect that has changed is how I see myself reflected in the eyes of others. In my day-to-day life, I am not always aware about my sensitivity to this social reflection, but I become aware of my own sensitivity, particularly in large gatherings of people whom I don’t know or have just met. In such cases, I find myself highly aware and sensitive to the looks I get from people around me, and when I am introduced to people, I almost automatically take mental notes of whether the people I meet shake my hand and how.*

*A more positive outcome of my self-perception and sensitivity to others is that I attribute some of my motivation to this social reflection. In high school, I was always one of the quiet kids in the class, raising my voice only to tell an occasional joke, but not to participate in the academic discussion. During my first year in college, I still was wearing my Jobst, a head-to-toe elastic cover designed to create pressure on the*

*recovering tissue, and which covered me completely with a brownish elastic panty hose-like material, leaving only holes for my eyes, ears, and mouth. The image the Jobst gave me was somewhere between a Martian and a bank robber.*

*In addition, from the way I moved and from the contraptions on my arms and hands, it was clearly noticeable that I was still undergoing treatments. Almost continuously, I had a strong feeling that when others observed me, they saw not only my injury, but that they were also making inferences that my appearance and intelligence were highly correlated. As a consequence, it was very important to me to show my peers that this correlation did not exist, and so I found myself participating frequently in class and even learning to enjoy it. Proving I was reasonably intelligent was important for me not only because of how I saw myself in the eyes of others; it was also important for my own self-definition. Losing my appearance made me feel a strong separation between body and mind, and since one part of this duality did not reflect who I considered myself to be, I held onto the part that was not changed—the part that still held for me the true definition of myself—my mind, ideas, and ways of thinking.*

*In addition to being a central part of my self-definition, my injury has also sparked interests in research questions concerning pain, pain tolerance, its aggregation, and its evaluation over time. In my first project in this area, I examined whether my own reflections – that I worry less about physical pain as a consequence of my long exposure to it – are applicable to a broader population of injuries, which it is.*

*Overall, I try to look at my injury as another experience, one of many that composes my life. This was indeed a powerful, painful, and prolonged experience, but it also has provided one of the most central “threads” of the way I understand myself and others. In retrospect, it is surprising for me to see how positively my life has turned out. I think it has turned out to be better than others have expected and defiantly better than I myself expected. I was able to find a flexible occupation that allows me to work more when I feel better and less when I don’t. I’ve also found much happiness in my personal life, again to a degree beyond my expectations (which I attribute to the incredible generosity of women in general and my wife in particular). Moreover, the pain I experience seems less difficult to deal with as time progresses. I have learned how to live with physical pain and, most important, I have learned how to structure my day around it.*

Overall, when one takes stock of one’s life after events such as the injury described here, it is interesting to ask whether overall well-being has changed after such an event. Some work on well-being suggests that people in general become used to new circumstances to an extent that is beyond their, and others’, initial estimates (Diener and Diener 1996; Diener and Suh 1997; Gilbert et al. 1998; Kahneman 1999; Schkade and Kahneman 1998). It has even been suggested that people who sustain a substantial injury are not much worse off compared to people who have not (Brickman, Coates, and Janoff-Bulman 1978). It is difficult to examine my accounts of my experience and propose that my well-being has not decreased substantially. On the other hand, it is obvious that I also attribute some positive aspects to my injury – leading a life that seems to be adapted to these new circumstances. Even the way I experience physical pain has changed my tolerance for it has increased, an outcome that is not unique to my experience (see

Dar, Ariely, and Frenk 1995).

Thus, it seems that my personal reflections are only in partial agreement with the literature on well being (see also Levav 2002). In terms of agreement with adaptation, I find myself to be relatively happy in day-to-day life – beyond the level predicted (by others as well as by myself) for someone with this type of injury. Mostly, this relative happiness can be attributed to the human flexibility of finding activities and outlets that can be experienced and finding in these, fulfillment, interest, and satisfaction. For example, I found a profession that provides me with a wide-ranging flexibility in my daily life, reducing the adverse effects of my limitations on my ability. Being able to find happiness in new ways and to adjust one's dreams and aspirations to a new direction is clearly an important human ability that muffles the hardship of wrong turns in life circumstances. It is possible that individuals who are injured at later stages of their lives, when they are more set in terms of their goals, have a more difficult time adjusting to such life-changing events.

However, these reflections also point to substantial disagreements with the current literature on well-being. For example, there is no way that I can convince myself that I am as happy as I would have been without the injury. There is not a day in which I do not feel pain, or realize the disadvantages in my situation. Despite this daily awareness, if I had participated in a study on well-being and had been asked to rate my daily happiness on a scale from 0 (not at all happy) to 100 (extremely happy), I would have probably provided a high number, probably as high as I would have given if I had not had this injury. Yet, such high ratings of daily happiness would have been high only relative to the top of my privately defined scale, which has been

adjusted downward to accommodate the new circumstances and possibilities (Grice 1975).

Thus, while it is possible to show that ratings of happiness are not influenced much based on large life events, it is not clear that this measure reflects similar affective states.

As a mental experiment, imagine yourself in the following situation. How you would rate your overall life satisfaction a few years after you had sustained a serious injury. How would your ratings reflect the impact of these new circumstances? Now imagine that you had a choice to make whether you would want this injury. Imagine further that you were asked how much you would have paid not to have this injury. I propose that in such cases, the ratings of overall satisfaction would not be substantially influenced by the injury, while the choice and willingness to pay would be - and to a very large degree. Thus, while I believe that there is some adaptation and adjustment to new life circumstances, I also believe that the extent to which such adjustments can be seen as reflecting true adaptation (such as in the physiological sense of adaptation to light for example) is overstated. Happiness can be found in many places, and individuals cannot always predict their ability to do so. Yet, this should not undermine our understanding of horrific life events, or reduce our effort to eliminate them.





### **Final Words for Now**

I presented a few aspects of my life as a burn patient, accompanied by research – and policy – related reflections on these experiences. The overall goal of this exposition has been threefold. First, it is important to gain a better understanding of what patients are experiencing as a consequence of illness, injury, hospitalization, and pain. By better understanding these experiences, we might be able to offset some of their adverse effects.

Second, the importance of this understanding will continue to increase as medical technology improves and as it becomes possible to save/prolong the lives of more people for longer periods, thus leading to a higher frequency of the type of existence described here. In the face of medical technology, more and more policy questions will become relevant. For example, under what conditions should people be treated? Under what conditions should their lives be prolonged? In order to answer these difficult questions and develop policies for treatments, it is important to consider not only what medical technology can provide, but also the life quality implications for patients. It is my hope that some of these issues will become a central focus for

investigation and policy in the years to come.

The third and final goal of this odyssey has been to describe a few of the subjective experiences that accompany such circumstances (observer-actor separation; experiences over time; control; effects of ends; memory for different emotions and for pain), in the hope of providing some insights regarding possible research directions into these psychological phenomena.

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