

PAINFUL LESSONS

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Based on my personal experience as a burn patient, in what follows I describe and reflect on some of the difficulties and challenges involved in extensive injuries and prolonged hospitalization.

Painful Lessons

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A large, full-length mirror, waited for me in the nurses' station. Having not walked more than a few meters for months, the hallway to the nurses' station was a true challenge, pain and difficulty increased with every step. I turned the corner and got closer and closer to the mirror, and finally turned and looked at myself. Legs bent and covered in thick layers of bandages; back completely bent forward; bandaged arms collapsed sideways. My twisted body looked foreign and detached from what I felt and knew was me. Still, the worst was my face. The whole right side was open flesh, yellow and red with pieces of tissue and skin hanging from it. It looked as if it were made from colorful wax that was in the process of melting. My eyes were pulled severely to the side. The right side of my mouth, and nose were charred and distorted, as was my right ear.

It was hard to grasp all the details. I just stood there and tried to take in the whole new me. Was the old me still in the image that looked at me from the mirror? I only recognized the left eye that gazed at me from the mirror—placed in this different and foreign body. During the treatments I had seen parts of my body so I knew how some of the scars looked. I had also been 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 this new reality.

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On what would otherwise have been a normal Friday afternoon, my life changed irreversibly in a matter

of 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 few seconds that forever changed my life, marked the starting point of a long and painful period of hospitalization. For the three years that followed, I faced not only hospitalization, numerous treatments, and pain but emotional turbulence as well.

Burns and their treatment 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 "academic reflection" of the experience, focusing on related research questions, and on implications for policies regarding the treatments of patients.

The Injury

The explosion comes from out of nowhere. Flames surround me. I can't see through the glowing white light of burning magnesium. Instinctively, I back away from the flames. Smoke permeates the room and although I can hardly see, I know my T-shirt is on fire. As if in a dream, I use my hands to put it out. Time slows down. I am thinking what to do next. Someone calls from the other side of the room and tries to guide me toward an exit. Realizing I am trapped, the flames bursting between the door and me, I run through the fire in order to escape. When I reach the exit, my clothes are once again in

flames. I remove the burning remains of my shoes, T-shirt, and trousers and make my way outside. There, standing in 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 completely black, but still has its familiar shape, and thus I am relieved, assuming (incorrectly as I will later discover) that it is generally fine. Looking to the left, the picture is very different. Large pieces of skin hang loosely from my left arm. The whole arm itself is white as the stone floor beneath me, with particles of chemicals and ash contrasting clearly against the perfect white skin. Only then does the unbearable pain in my arms and legs overcome me. Trying to minimize my pain, I lie as still as I can, even measuring my breath in order to eliminate any unnecessary movements. Soon the medical team arrives and carries me away.

Reflection / Detachment: Initially, the entire experience seemed disconnected from reality. I felt as if I was in a dream, playing a role in a movie scene, observing my own behavior, but not experiencing any of it as an active participant. During these detached moments, subjective time passed slowly and each decision seemed to have been weighted and examined deliberately and carefully. It felt as if I had plenty of time to decide how to put out the flames, what part of the flames to distinguish first, and how to escape. A second aspect that made the experience seem less real was the relatively low level of pain I experienced 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 pain. The fact that I was able to leave the building and walk to the front of it becomes an even stranger phenomenon when you consider that it took many months before I was able to walk this distance again.

What is the nature of this detachment? One possibility is that both the perception of “slow motion” and the separation I felt between myself, and the person experiencing the events was due to the difficulty of comprehending this new and unexpected reality. Digestion of information can be difficult when individuals are subjected to experiences that are highly unexpected and for which they have no “scripts” for how these events will unfold and progress. Such difficulty in processing the information can, in turn, create the subjective feeling of “slow motion,” where each piece of information is separately recorded, digested, and carefully attended to. The same lack of scripts can also make the new and unexpected events difficult to interpret as being self-relevant, resulting in the actor/observer discrepancy that I felt during these moments.

Reflection / 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 with intense pain, waiting for help to arrive. How was it that I was able to get away from danger without much pain, and that the pain kicked in with all its intensity only once I was away from the flames? Was it simply a convenient coincident? The pioneering work of Beecher (1) suggests that the experience of pain is regulated by situational determinants, including the circumstances of the injury. In his research, Beecher compared the extent of the pain experienced, and the requests for pain-relievers, between individuals injured in battle and individuals injured in car accidents. Despite the similarity in the objective state of the injuries in terms of magnitude, Beecher found that following battlefield injuries individuals consistently reported less pain and

asked for substantially fewer painkillers. Beecher attributed these results to the “happiness” soldiers felt about escaping the dangers of the front lines, a benefit that was not available to the car accident victims.

A different interpretation of Beecher’s results could be based on the functional role that changes in pain tolerance could achieve for the person experiencing the pain. From this perspective, immediate pain is useful in preventing the individual from harming himself further, and delayed pain, as in the description above, is useful in allowing the person to function long enough to remove himself from harm’s way. Only once away from danger, is the functional role of high pain tolerance eliminated, and do the benefits for reducing any movement become larger—at which point the debilitating experience of pain strikes. From this perspective, the combined functions of immediate and delayed pain have different implications for different causes of injury. For example, it is obvious that delayed pain would greatly benefit a soldier in the battlefield, but not a person injured in a car accident (in fact, leaving the accident scene in such cases would likely cause unneeded stress on the injuries). While the idea that our mind “knows” when to inhibit pain and when to allow it, is compelling, it is not clear what mechanism could allow this differentiation.

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 in the hospital. From then on I will be given a bath every day, with the exception of the days I am lucky enough to be in the operating room (which makes the operations themselves 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

memory to record and comprehend, and it always proves worse than my expectations. The bath water is purple from the disinfectant 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 begin removing the bandages. In the absence of skin, the bandages are stuck to my raw bleeding flesh and their removal is long and painful. The nurses usually start with my legs and proceed to my arms, chest, and finally the most painful of all, my neck and face. Throughout the removal process, the nurses and I negotiate about the speed of the bandage-removal and about breaks we might take in order to allow me to catch my breath and brace myself for the removal of the next set. The speed at which the nurses remove the bandages is almost always too fast. They hold on to the edge of a bandage and quickly rip it off. This method causes me relatively 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 altogether, I also want to take a break from time to time, in order to calm down and prepare myself for the pain to come. The nurses and physicians generally oppose both of these suggestions. They argue that finishing the bath as fast as possible is the best approach for me. About an hour after I enter the bath, the process finally ends. The metal forklift raises my stretcher out of the tub and the nurses apply a layer of Siverol (an ointment for burns) to all my exposed areas, which is about 70% of my body. New bandages are applied, and I return to my room for physiotherapy and other arduous treatments. Meanwhile the time is clicking until the whole procedure is repeated again the next day.

Reflection / 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 (2-3). Research in this area has revealed that the overall pain of prolonged experiences is largely influenced by the final intensity of the experience (4-6) and its rate of change (7-8). 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 research, it is likely that the optimal way to deliver treatments to patients is to initially deliver the most painful parts of the treatment, and then move on to the less painful parts of the treatment.

Reflection / Breaking up treatments: A second issue that arises from the description of the bath procedure concerns the question as to whether breaks during such treatments would have been beneficial. Would it benefit patients in such situations to take short breaks? Or were the nurses right in delivering the treatments in one prolonged session? Initial evidence suggests that the answer to this question, at least partially, depends on whether the breaks moderate the pattern of the pain (9). These initial results suggest 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.

Another consideration related to taking breaks during treatment is the patients' capacity to renew their coping ability. There is no question that painful treatments are taxing, and that a patient's coping ability is diminished during the treatment (10-11). The question is how deep is the depletion of their coping ability, and what type of break could best renew it. If the coping ability is just partially used—short breaks, allowing the patient to catch his breath, might provide a sufficient period for recovery. However, if the coping ability is completely depleted, longer breaks might be required. How long is long? It depends on how the coping ability is renewed. For example, if the 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 the coping ability has a relatively short regeneration period, multiple and frequent breaks throughout the day would indeed be beneficial. Of course, the precise nature of coping ability may be more complex, as it is likely to depend on the individual patient and the specific treatment required. A final complexity regarding the regeneration of coping ability during breaks is that the fear of the next treatment could inhibit coping ability recovery. In any case, it is clear that a better understanding of the individual and their specific treatments is needed in order to design a treatment plan, whether broken up or concentrated.

Reflection / Duration of treatments: A separate recommendation from this research on "hedonic calculus" is that when delivering treatments, it may be desirable to reduce the momentary intensity in favor of prolonged durations. After all, if individuals

mostly pay attention 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 seems that doubling the duration of a given experience (e.g. repeating it twice) is perceived as less painful than if we doubled its intensity (but see also 12-13).

Reflection / 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 and even as causing less damage to the natural immune system (14-16).

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 profoundly different. The influence of the nurses on my well-being started hours before the bath treatment, the moment I learned who was going to be the nurse on duty for my bath. On good days, when the nurse that gave me 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 experience an intense anxiety that increased as the treatment time approached and this anxiety became more exacerbated throughout my hospitalization period. The difference between these two nurses was so vast that I continuously “fished” for details about the nurses’ shift schedules, and used this information to arrange conflicting treatments during the times the “no-control nurse” was on duty or prearrange with other nurses for them to treat me earlier in the day before the tyrant could “get me.”*

First Operation

Midmorning, one of my physicians enters my room accompanied by two nurses. He informs me that my right arm is so swollen that the inside pressure is preventing blood flow to my hand. He neatly arranges a tray of what seems to be dozens of scalpels and explains that in order to reduce the pressure, he has 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, he has to perform the operation while I am in my hospital bed and without anesthesia. I am frightened to no end. In an attempt to comfort me, the physician explains that since most of the nerves in my right arm are dead anyway, 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 and shoulder in place, the other holds my right shoulder and arm and presses it down with all her weight. I watch the scalpel advance slowly along my arm, creating a deep tear. I see

* At one point I went on a date with a lovely girl and during the course of the evening, I told her about the nurses in the burn department. She asked the name of the awful male nurse, I told her his name and it turned out that he was her father. Needless to say, the evening ended rather quickly and I did not see her again.

the physician cutting me with the sharp scalpel, but I feel as if he is tearing me open with a blunt garden tool. The intensity of the pain catches me by surprise and leaves me gasping. It is unbelievable, unlike any pain I could have ever 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 beg them to stop, "You are killing me!" I cry out. No matter what I say, no matter how much I beg, they do not stop. The pain grows stronger. "Stop!" I scream 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 slowly to 10 and that when I reach 10 it will be over. I start counting as slowly as I can bear. 1, 2, 3... Time slows 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 is made. 7, 8, 9... I will never forget the tearing flesh, the excruciating anguish, and the waiting... as long as I can... before yelling... TEN!

The physician stops cutting. The nurses release their hold on me. I feel like an ancient warrior who has conquered his suffering with brave nobility. I am 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. I have used all of my energy on convincing myself to hold on as long as possible, certain that the 10-count would bring the end. I perceive the impending pain, which a few seconds earlier seemed manageable, with full-blown terror. How can I survive this again? Now? "Please, I will do anything. Just stop," I beg. The repeated cutting terrifies me. I am helpless. I cannot control myself. I scream, cry, and shout all at once. But, I

have no say in the matter. This time they hold me even tighter. "Wait, wait," I try for the last time, but the doctor proceeds silently with his cutting. He "finishes" the arm and then makes two cuts in each of my fingers. I do not know how much time is passing but I continue to count 1, 2, 3, 4... and shout when I reach 10. I count over and over until the physician finally stops cutting. My hand is unbelievably sensitive and the pain is endless. Bleeding and crying, I am left to rest.

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At the time, I didn't understand the importance of this operation. A few months later, I found out that some of the physicians wanted to amputate my arm and that the surgeon who 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, while having other surgeries on that arm, if he had made the right decision for me.

Reflection / 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 the pain will end once a target has been reached, 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 endpoint can also increase the feeling of control as well as decrease levels of fear and dread, all of which can lead to 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 once asked 60 gym-goers to hold, using their dominant arm, a 5 lb. weight for as long as they could. Next, I asked each of them to repeat the process using their other (non-dominant) arm for a duration that was thirty seconds longer than they had been able to hold the weight using their dominant arm. In this second trial, respondents were randomly assigned to one of three counting procedures. In one treatment I counted up for them until they reached their goal time (or until they stopped of their own accord). In another treatment I counted down until they reached zero (or until they stopped of their own accord). Finally, in the last treatment I did not count at all. What did the results show? Counting helps, and counting backward to zero helps even more. Participants in the down-counting condition managed to hold the weight for the longest time (24.7 seconds more than in their dominant arm). Participants in the up-counting condition managed to hold the weight for a shorter time (5 seconds more than in their dominant arm). 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 weight was held with the non-dominant arm was held for less time than the dominant arm (22.6 seconds less than in their dominant arm).

Several questions arise from my own experience and these findings. Why does knowledge of the endpoint improve coping ability and motivation? What tools can we provide patients with to help them 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, 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 near? Finally, what types of activities could benefit from the effects of “end-knowledge”? Do these include domains that are not limited to physical pain such as retirement savings, exercising, and better work habits?

Additional Reflections / 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 a vague memory of its intensity and the residual emotions that these memories evoke. I remember the scalpel cutting through my arm and hand. I remember the pain during my daily baths, 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 felt during those years, I am also 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 words now, my state of consciousness changes. There is clearly sadness during these experiences, but 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, and replays them for me.

Additional Reflections / Memory of Emotions

In addition to pain, I experienced other emotions during my three years in the hospital. My memories of some of them, 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 them, they left no memory trace for me to feel or reconstruct my past emotions. The cognition of knowing I 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, and my reactions to the people who shook (or did not shake) my hand.

The differences in memory for these two types of emotions suggest that there might be differences between the memory processes for non-social emotions such as fear and helplessness, and social emotions such as embarrassment and negative social comparison. Most notably, memories for social emotions seem to be more intense and longer lasting. Perhaps since social emotions are based on the reflection of one's own image in the eyes of others they require more elaboration (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. A different account for the differences between the memory for non-social emotions and social emotions might be the frequency with which they occur. During my

hospitalization, pain, helplessness, fear, and hopelessness were frequent and recurring emotions, while the social emotions were experiences with much lower frequency. It is possible that the rarity and relative uniqueness of these emotions makes them more salient in retrospect.

Additional Reflections / Long-Term View

My injury took place many years ago, and as time goes by, more of my life has been spent in this physical state. From time to time I try 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 (or at least I am not successful in managing to do so), but I do allow myself to see a few advantages in this fundamental change to my life. These beneficial 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 is 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, another 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 they do so.

A more positive outcome of my self-perception and sensitivity to others is that I attribute some of my academic 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 was still wearing my Jobst suit, 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 suit created on 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 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 over time 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.

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 has also provided one of the most central “threads” of the way I understand myself and others (and it has also sparked many of my research interests). In retrospect, it is surprising to see how positively my life has turned out. I think it has turned out to be better than others expected and definitely better than I myself expected. I found a profession that provides me with wide-ranging flexibility, allowing me to work more when I feel better and less when I don't—reducing the adverse effects of my limitations on my ability. 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). At the same time, there is still not a day in which I do not feel pain, or realize the disadvantages of my situation, but to some extent I have learned how to live with physical pain and, most importantly, I have learned how to structure my day around it.



Final Words (for Now)

I presented a few aspects of my life as a burn patient, accompanied by some 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 experience as a consequence of illness, injury, hospitalization, and pain. Hopefully, by better understanding these experiences, we might be able to offset some of their adverse effects.

Second, the importance of understanding the long-term effects on patients 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 related 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 final goal of this essay 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 phenomena.

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