

**DEATH**

**AS DEFIANCE**

**AN ANARCHIST CRITIQUE OF MODERN MEDICINE**

**FERAL DISTRO**

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“A cell never dies in isolation, but in clear view of its peers...a cell understands better than we humans do the consequences of overstaying one’s welcome. While we humans aspire to immortality, to a cell, immortality is the worst fate possible.” - Haider Warraich, M.D.

### *Modern Death: How Medicine Changed the End of Life*

“Since the introduction of modern technology, the hospital has lost its aura of being a place of comfort and has instead become an establishment resembling a factory, where illnesses are taken care of, rather than human beings...The underlying premise of the hospital’s organization of medical care is consistent with the central motivational values of the technological consciousness, namely, that the vital needs of human beings are reducible to technologically manageable components.” - David Wendell Moller

### *On Death Without Dignity: The Human Impact of Technological Dying*

The ways in which we die and the culture surrounding death are a reflection of the values of society. This society attempts to manage the inherent chaos of death by wrapping it in bureaucracy and medication, and by attempting to reject it as long as possible. This does a disservice to us all, but especially to us when we’re in the process of dying. Dying is seen as dangerous precisely because it is something out of our control. Without returning to old folkways of death and reversing the banality of death, we will continue on the same path, re-affirming capitalist ideals of continuous growth and immortality which serve to exacerbate the ontological terror of impending death. There is no communality to support the dying through the turmoil and physical pain that no amount of medicine will, or should, completely rid us of.

Hospitals, and what we know as contemporary health care, are often missing from critiques of civilization, partly because they are seen as healing and life-affirming spaces, rather than as a locus of state and social control. It is easy to isolate the aspects of civilization that are imposed on us, which we learn to rebel against as we feel its pressures; It is much harder to suggest to someone that medical intervention isn’t inherently good. People believe in the Hippocratic oath that doctors take, to “do no harm.” It is something most of us grow up with, from prenatal exams and on.

With this in mind, it is no surprise that medicine is often either absent from anarchist criticism or defended as necessary. The promise that science holds the secret to eternal life has replaced the non-secular myths of immortality. The dying are now behind closed doors, their stench and emotional turbulence hidden, all while we soak up images of youth and beauty.

There are strong arguments to why medical institutions should be placed in the same category as factories and prisons. Most come straight from patients and physicians themselves, but there are also some from critical thinkers who name what was lost when science married medicine. As Dr. Warraich, author of *Modern Death: How Medicine Changed the End of Life* observes, “medicine had been an art for thousands of years,” but by the late 20<sup>th</sup> century it became a science as it intertwined with technology, and “the number of interventions that physicians could perform began to rise exponentially. Almost in parallel, discoveries started to be made that fundamentally altered humanity’s conception of life.”

To see death and sickness out in the open, as has been the case for most of human history, is to destroy the modern myth of technological progress. The closer people come to death, the more they place their hopes in the finding of a cure, as if death itself

of anger, vulnerability, fear and emotional turbulence that characterize a personalized response to dying are rendered insignificant through the standardized objectification of a patient’s identity. (David Wendell Moller, *On Death Without Dignity: The Human Impact of Technological Dying*, 2018, pg. 53)

One step to creating a culture that respects death is to simply acknowledge how hospitals, the ideal of wellness, and the technological management of the sick and dying, are all central to keeping the current power structures in place. To really change anything, that technological management must be dismantled, and we must move beyond the idea that every illness and disease and dysfunction must be cured. The dying person must be centered, not for the management of symptoms, but rather to give them the space and support to experience all the turmoil and emotions that always exist along with pain. Even “death with dignity.” is like all reforms, a more subtle way to continue the management of people through the death process.

When envisioning a new type of death culture, or any aspect of life that civilization has robbed of meaning, we don’t want to simply create a mirror image of the set of values that led us here. One patient Moller interviewed said of his pain: The pain is evil. It’s destructive, bad, and even demonic. The cancer makes me nervous, anxious, obsessive. The pain and suffering is so bad that it must be bad, that it must be evil. I often ask, what did I do to deserve this? I can’t see any reason, I really can’t. If I had an explanation, it would set my mind at ease. Without it there is just confusion; helplessness sometimes. I just can’t be sure that there is a God. It’s disturbing and uncomfortable. Really, there is no meaning to the pain. Pain like this has to come from the devil. At certain times, I feel that the pain is punishing me. (David Wendell Moller, *On Death Without Dignity: The Human Impact of Technological Dying*, 2018, pg. 72)

Life-prolonging measures would be more accurately referred to as death-prolonging measures. The idea that primitives lived short, nasty and brutish lives is still alive and well among anarchists, though that’s been refuted by anthropologists, from Marshall Sahlins to David Graeber and David Wengrow in *The Dawn of Everything*. Even if life was shorter, the enforced elongation of life has arguably led to more suffering, and in my opinion, lives that are more nasty and brutish than those of many of our ancestors.

Any vision of a truly free life will place spiritual significance on death rather than regarding it as a scourge and social evil, and will foster fellowship among the dying and the living. Just as today we recognize abortion as a sometimes-difficult choice but one that the individuals concerned get to make, the sick would fully exercise their bodily autonomy and put it into practice without stigma. Groups such as the Hemlock Society, a pioneering right-to-die organization that published the incredibly important book *“Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying,”* and in 1981 published the first (possibly last) openly-sold “suicide guide” show us the way. As in midwifery, anarchists should learn to guide our own through suffering and death, and at least one group, Distinctly Dionysian, did just that by publishing *How to Bury an Anarchist*, which explains human composting. Most of all we need to listen to the words of the dying and be open to all the anxieties, fear, and ontological crises that will inevitably be part of the dying process for all involved. As one terminally ill man remarked when given the choice between dying and being kept alive artificially, “there are worse states than death.”

this:

“I think the reason why death had become something to be hidden away is not that anxiety has somehow been displaced or that repressive mechanisms have been modified. What once (and until the end of the eighteenth century) made death so spectacular and ritualized it so much was the fact that it was a manifestation of a transition from one power to another....Now that power is decreasingly the power of the right to take life, and increasingly the right to intervene to make live, or once power begins to intervene mainly at this level in order to improve life by eliminating accidents, the random element, and deficiencies, death becomes, insofar as it is the end of life, the term, the limit, or the end of power too. Death is outside the power relationship... Power has not control over death, but it can control mortality. And to that extent, it is only natural that death should now be privatized, and should become the most private thing of all. In the right of sovereignty, death was the most spectacular manifestation of the absolute power of the sovereign: death now becomes, in contrast, the moment when the individual escapes all power, falls back on himself and retreats, so to speak, into his own privacy. Power no longer recognizes death. Power literally ignores death.” (Foucault, *Society Must Be Defended*, pg. 248)

Modern healthcare has its own cultural values and biases, which need to be exposed and reckoned with, as much as its racism and paternalism. Gynecology and obstetrics needn't be isolated as sites of contention between our bodies and the state, but included in the larger collection of medical practices that keep us waking up to get us to our jobs each morning, while robbing us of any spiritual anchors that would have guided us through the confusion and pain of illness and death, and that help give meaning to suffering.

Moller diagnosed twelve symptoms of our detachment from the dying process including:

- the sense of isolation of dying patients and loved ones
- the devaluation of the dying experience
- the downward path of pain, suffering, and deterioration experienced by the dying person
- the feelings of rejection as a sexual being
- romantic, sentimental, and overly-inflated expressions of grief

In 1986 a group called Americans Against Human Suffering was founded and launched a campaign for the “California Death with Dignity Act. It took until 1992 for Proposition 161 to be placed on the ballot. It would have allowed physicians to assist patients hasten death by prescribing medications for self administration by terminally-ill patients. California voters defeated the measure 54 to 46 percent. Other states would follow in attempting to pass their own death with dignity acts.

The problems with the idea of death with dignity is while that it is an alternative to the cold, impersonal nature of hospitals and assisted-living facilities, it ultimately falls within the same logic: as a management system not just for the pain of the body, but also the painful emotions that inevitability arise.

The hospice has established new and specialized professional roles of caring for the dying, namely, hospice medical director, hospice chaplain, hospice nurses, and hospice volunteers. In this way the hospice, while seeking a more comprehensive approach to patient care, is still situated within the broader framework of specialization and compartmentalization of care...The very human and potentially meaningful expressions

were a disease. When tragedy strikes and someone is revived by heroic measures, but if taken off life-sustaining devices will surely die, people pray for a miracle and are confused when they are told there won't be one. This leads to some horrific cases of what I call abuse through medical intervention, that could easily be mistaken for a plot from a Cronenberg film. If you want to learn about the normalization of cruelty, look no further than medicine.

Two stories that epitomize this type of medical abuse are the cases of Karen Ann Quinlan and Jahi McMath, which are complete opposites. In the Quinlan case, they were fighting to have their daughter taken off the ventilator that kept her alive, while the McMaths were pleading to have anything and everything done, no matter what that looked like, even knowing that she would never come out of a comatose state. One woman is held hostage by her physicians and the state, the other by her family. Tragedy, sickness, death... these all will continue no matter how Utopian a society. Of course this isn't just a problem with technology, but is created by a complex set of factors that are a reflection of the culture that molded us.

### **The Tragedy of an American Valium Queen**

Quinlan's case, which would become the defining one of the right-to-die movement, is quintessentially American. She was born in 1954 and adopted into a middle-class family. She went to high school, played sports, dated and attended mass with her family. Something changed when she lost her job at a ceramics factory, and with the pressures of moving from low paying job to low paying job, her life spiraled into alcohol and pills as she struggled to maintain.

This was her life on April 14, 1975, when she was at a bar partying with friends. She was determined to fit into a dress, so the days before she had barely had anything to eat or drink. Then she took some tranquilizer pills and drank some gin. She collapsed, and stopped breathing. As Warraich notes, what proceeded showed just how far medical care had come over a short period of time.

First, her friend performed mouth-to-mouth resuscitation, but by then her brain had been without oxygen for at least two fifteen minute periods. EMS came took her to a local hospital where they hooked her up to a mechanical ventilator. Doctors observed that her pupils were fixed (did not respond to light), and that she didn't respond to pain. After three days, a neurologist concluded Karen was comatose, with evidence of “decortication”, a condition that represents extensive damage to the higher parts of the brain. It presents itself as legs stiff and straight and arms flexed tight.

From here on, Karen's condition only got worse. Despite the nasogastric tube going down her nose and into her stomach to provide her food and medicine, within the next few months she would drop from 115 lbs to 70. Her parents, practicing Catholics, were deeply struggling with the situation and involved their priests. They came to the decision to place her life in God's hands. Others had been in their shoes, but this time, it would find its way into the public eye. For months Joseph Quinlan had been requesting that Karen's physicians withhold care and take her off the ventilator, and went so far as to draft a document releasing them from any liability should they fear a lawsuit. But the doctors refused. Warraich goes onto describe her new “second life” (social death): All the physicians involved in Karen's care agreed that her prognosis was extremely poor. They also agreed that the chances of her reverting out of her coma were next to nil... she was in a state where her quality of life was almost subhuman. She was dependent on a machine to help her breathe.

She needed artificial nutrition, in spite of which she weighed only seventy pounds. And it was clear that there was no available technology or intervention that would help her regain any of her normal functions. (Warraich, pg. 75)

The Quinlans knew Karen would have been against such extraordinary life-sustaining measures, so they filed a lawsuit, which, however came at a point when Nazi euthanasia programs were fresh in American's minds. Just a few weeks earlier, a New Jersey Court had not allowed a woman with terminal leukemia the right to refuse a feeding tube. Looking back on her daughter's life in an interview, Julian Quinlan could hear her daughter telling her " 'This is what I want, mom. Please get rid of all these things.' She tried so hard to release herself. She would twist her head and try to release it." (10/31/2021, <https://www.dailyrecord.com/story/news/2016/04/03/julia-quinlan-mother-karen-reflects-40-year-milestone/82524984/>)

In Karen's case, because she did not have an entirely flat EEG and could breathe spontaneously from time to time without oxygen from the ventilator, everyone agreed that she was not dead. However, the court actually refused to recognize Joseph Quinlan as the person who should make decisions on her behalf, and appointed a part-time public defender as Karen's legal guardian. One of the justices in the case voiced his opinion on the removal of the ventilator: the decision should be left to the treating physician. "I am satisfied that it may be concurred in by the parents but not governed by them." This decision to remove Joseph Quinlan as legal guardian would bring the case to trial and after two weeks, the Justice returned with his ruling: "There is a higher standard, a higher duty, that encompasses the uniqueness of human life, the integrity of the medical profession and the attitude of society toward the physician, and therefore the morals of society... There is no constitutional right to die that can be asserted by a parent for his incompetent adult child." (Warraich, pg. 77-78)

What this Justice was saying was it was in the state's best interest to preserve life, and that matters more than anything else.

Meanwhile, images of Karen's state in the hospital were contrasted with the picture that had come to define her from high school in which she embodied a wholesomeness that gets the attention of the media. Her posture was described as "fetal" and "grotesque." Warraich quotes a neurologist describing her as an "anencephalic monster."

The Quinlan case became yet another example of how powerful images can be in shaping discourse. "Descriptions that were vile, painting Karen in an inhuman fashion, were employed to amplify her suffering and to demonstrate how cruel it was to unnecessarily sustain her." (Warraich, pg. 79)

Eventually, the state's Supreme Court would rule in favor of the Quinlans, once the argument became about violation of privacy (a ruling that, like *Roe v. Wade*, brought patient rights into the spotlight) and Karen was removed from the ventilator. Surprisingly, she would go on to live ten more years in a nursing home (although still being fed through a feeding tube, which the Quinlans allowed) before dying from pneumonia with her mother at her side.

### **Jahi McMath and the Horror of Medical Technology**

For the McMaths, the nightmare began December 9, 2013, when they took their daughter Jahi to Oakland Children's Hospital for an elective surgical procedure to help her sleep apnea. To help her breathe better, several structures, such as her tonsils, uvula, turbinates, and adenoids, would be removed from her throat (a procedure the

media portray as a "routine tonsillectomy"). What happened afterwards isn't public, as the hospital was restricted by her parents from releasing any information. What we do know is, Jahi appeared fine to her mother until she started bleeding from the throat where the surgery had been performed. She was immediately transferred to the ICU, where she suffered cardiac arrest. On December 12, just three days after she came to the hospital, Jahi was declared brain dead by the physicians taking care of her. She fulfilled all the criteria for brain death, verified by external state-appointed experts as well. Her parents, though, refused to accept this assessment and implored the doctors to place a feeding tube and to perform a tracheotomy. The hospital denied that request. Jahi's parents went to reporters and took over the airways. They acquired funding and support from groups around America campaigning against the modern legal and medical definitions of death. They also petitioned to have Paul Byrne, a neonatologist committed to opposing brain death and transplantation, to carry out his own investigation, but the court refused this. As the court battle continued, Jahi's body kept degrading. Her intestines started sloughing off and the only bowel movement she had for weeks was in fact the lining of her intestines passing out. Her skin started to break down, and her blood pressure and body temperature swung wildly without any control from upstairs. The court finally delivered its verdict, agreeing that Jahi was in fact dead and that the hospital had the right to release her body to the coroner. After Jahi's body was released, she was transferred to a nursing facility in New Jersey, the only state to allow medical care for patients declared brain dead." (Warraich, pg. 96) (Jahi passed away June 22, 2018, after doctors found internal bleeding due to kidney and liver failure. They removed her from life support, allowing her to die).

Growing up, I remember watching *ER*, the show that really started the trend of hospital TV. After reading the words of those who've experienced terminal illness and life-threatening injury, and who've spent much of their lives dealing with the Western medical system, I now see how sanitized the show is. People are brought back from the brink, healed from illness, or die, but the true ugliness of life-sustaining measures and the grim reality of death is absent. Interestingly, the same year *ER* began airing, Jack Kevorkian's compassionate acts of euthanasia were being challenged in court, a total of four times between 1994 and 1997. Each time he was acquitted, until he did a 60 minutes interview in 1998, where the world witnessed him inject a patient (suffering from amyotrophic lateral sclerosis) with a cocktail of drugs that would end his life. Despite winning the visual war by showing the peaceful death of "a patient suffering to the extent that he couldn't take a single breath without discomfort", the video got Kevorkian jailed for manslaughter.

That fairly peaceful assisted death can be contrasted with the ugly reality of attempting to revivify someone. There's a reason family members are rushed out of hospital rooms when someone experiences cardiac arrest. Bringing someone back from the brink of death is violent. Sometimes efforts are successful and their heart starts beating again, but whether or not this person will live the same life they had before is another matter altogether. Once you have received "heroic measures," odds are it is too late for any recognizable recovery.

Why is contemporary medicine held sacred, even among those who are critical of similar bureaucratic structures? How have hospitals become omnipotent forces and why do people continue to dismiss the centrality of the sick and dying body as it concerns state control? Foucault believes that death "has become the most private and shameful thing of all", more taboo than sex." He goes on to provide an explanation for