From Sin to Treatment: A Very Brief Survey of the Relationship Between Political Power and End-of-life Decisions in Western Societies

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Abstract

Death and the circumstances under which one dies have been one of the most prolific themes in literature, the arts, and science in Western societies. Up until now, end-of-life practices in the West have relied more on curative treatments than on palliative care. The legalization of intentional practices such as euthanasia and assisted-suicide, in particular, is still a highly controversial topic. All this may lead us to think that the preservation of life and the intrinsic value of human beings inform current medical and political paradigms.

In this article, I explore how Michel Foucault's concepts of biopolitics and biopower have foregrounded the way political power has expanded its scope from the juridical right to "make live or let die" to the power of promoting life or rejecting it. To Foucault, death is the most secret part of our private life; it is where power meets its limit, thus the need to control every aspect of it, especially end-of-life decisions. I also illustrate my brief survey with three true life stories that may help us question the extent to which the contemporary organization of medical care may or may not be instrumental to political power in fostering the loss of autonomy of an individual facing death.

Keywords: death; biopower; biopolitics; end-of-life practices; autonomy.

Resumo

A morte e as circunstâncias em que alguém morre têm sido um dos temas mais prolíficos na literatura, nas artes e na ciência, nas sociedades ocidentais. O final de vida nestas sociedades tem recorrido mais a tratamentos para curar do que a cuidados paliativos. A legalização de práticas intencionais tal como a eutanásia e o suicídio assistido continuam a ser um tema muito

controverso. Tendo tudo isto em conta, é de esperar que a preservação da vida e o valor intrínseco do ser humano estejam na base dos paradigmas que sustentam a ação médica e política.

Neste artigo, explora-se a forma como os conceitos de biopolítica e biopoder de Michel Foucault permitem entender a expansão do poder político do direito jurídico de "dar a vida ou deixar morrer" ao poder de promover ou rejeitar a vida. Para Foucault, a morte é a parte mais secreta da nossa vida; é onde o poder conhece o seu limite, daí a necessidade de controlar todos os seus processos, especialmente as decisões de término da vida. Serão ainda apresentadas três histórias de vida reais que nos poderão ajudar a questionar até que ponto a organização contemporânea dos cuidados médicos pode ou não ser instrumental para o poder político promover a perda de autonomia de um indivíduo prestes a enfrentar a morte.

Palavras-chave: morte; biopoder; biopolítica; práticas de término da vida; autonomia.

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On 14 January 1998, Ramon Sampedro sipped his drink mixed with cyanide using a straw and a cup left by his bed. He had been paralyzed from the neck down since he was 25 years old and had been bedridden for twenty-nine years. The next day a friend who had been helping him with his daily routine since he had moved to La Coruña, Spain, found him dead. In fact, his friends had videotaped his suicide as evidence of Sampedro's voluntary act and no foul play from their part. In the video, he can be heard saying "When I drink this, I will have renounced the most humiliating of slaveries: being a live head stuck to a dead body." Yet, in the eyes of the Spanish law, Ramon Sampedro and his friends had resorted to assisted suicide, an illegal practice in Spain. In the following days, one friend was even arrested but soon released. Some years earlier, though, Mr. Sampedro had fought in the courts to be helped to die but in vain.[1]

Real cases like Sampedro's may lead us to re-evaluate to what extent the contemporary organization of medical care concerning end-of-life decisions in Western societies is instrumental to political power in fostering the loss of autonomy of an individual facing death.

The controversy is not new, and the sciences and the humanities have offered numerous for and against arguments on the legalization of practices like euthanasia and assisted suicide. In early modern Europe, literary works like Sir Thomas More's *Utopia* (1516), for instance, offered an imaginary account of an ideal society where the terminally ill were granted the right to make their own end-of-life decisions. In

practical terms, patients were counselled on which end-of-life decision would be best: the medical care and comfort provided by palliative care or to deliberately terminate life through euthanasia or assisted suicide.[2] Both forms of self-killing should be pursued under the advice of ministers and officials, on the one hand, and the supervision of a physician, on the other.

It soon becomes apparent, however, that the latter option is strongly encouraged because the terminally ill person "is now unequal to any of life's duties, a burden to himself and others" (More 78). Also, if the individual decided to shun such third-party interventions and commit suicide, she or he would not be worthy of proper funeral rites and burial. The dignity of a person is, in fact, deeply tied to the maintenance of an ideal social order (Trousson n.p.). The need to control the body and, consequently, society has been central to the utopian imagination because utopian projects have treated death and illness either as a source of instability and disorder or as an issue that must conform to strict rules (Fortunati and Franceschi 186).

To Michel Foucault, on the other hand, death is the most secret part of our private lives; it is where power meets its limit, thus the need to control every aspect of it, especially end-of-life decisions (248). Foucault's concepts of biopolitics and biopower have foregrounded the way political power expanded its scope from the juridical right to "take life or let die" to the power of promoting life or rejecting it (241). Moreover, he argues that suicide in any of its forms – suicide, euthanasia, assisted dying – has been considered a crime because it imperils the right of political entities to decide who lives and who dies (Ryan et al. 45).

In the last two centuries, death and dying have become more of a medical and legal issue and less of a religious matter. And, in fact, the concept of euthanasia, or "well dying," has also changed from the Christian point of view of death as a blessing from God to the central role of the physician in the process of death. From the nineteenth century onwards, in particular, the medicalization of death has meant that doctors assist the individual in the act of dying and provide a painless death. Consequently, the process of dying has almost ceased to be a family event at home to become a medical event supervised in a hospital (Ryan et al. 46). Moreover, even though euthanasia and assisted suicide have been legalized in a few Western countries, some have argued that the legalization of self-killing practices may have less to do with individual autonomy than with contemporary forms of biopower.

First, it would be useful to go back in time in order to understand which events and worldviews gave rise to current assumptions on self-killing. Second, I will briefly discuss Foucault's concepts of biopower and biopolitics. Third, some factors and arguments that influence how end-of-life decisions are legally, medically, and personally understood and dealt with nowadays will be discussed.

A Very Brief Genealogy of Self-killing

The ancient Greeks condemned acts of self-destruction, except in cases of acute physical or mental suffering. However, the Hippocratic Oath that still informs medical ethics today was also formulated in ancient Greece by Hippocrates. It condemned self-destruction or any assistance to the act of dying: "I will neither give a deadly drug to anybody if asked for it, nor will I make suggestions to this effect." Moreover, whereas Socrates accepted self-killing in some cases, Plato and Aristotle were against it. Notably, Aristotle based his views on the idea that the body belonged to the gods and to the state, thus the individual did not have the right to take his own life.

From their part, the Romans punished self-destruction with an exception made to the cases of *taedium vitae*, a state of mind similar to depression. This rule did not apply to slaves though, since they were considered property. The Stoics, on the other hand, had a very different standpoint: not only did they advocate the right of self-destruction, which should nonetheless happen after careful thought, but they did it with the help of a trained technician (Ryan et al. 44).

The Bible follows the Platonic tradition in the sense that the prevailing idea about life is that it belongs to God (Ryan et al. 3). In general, both the Old Testament and the New Testament depict self-killing only under special circumstances, namely when the individual disobeyed God's will and, thus, could not express his or her own regret except through death. In the fifth century, Saint Augustine of Hippo, one of the founding fathers of the Church as we know it today, condemned self-killing on the grounds of the fifth commandment: "You shall not kill." He argued that taking one's life was a way of questioning God's authority, and that the consequences would be to have no funeral rites or burial.

In the thirteenth century, influenced by Saint Augustine of Hippo and Aristotle, Saint Thomas Aquinas posited that any form of suicide was against God and society. During the Middle Ages, Aquinas' viewpoint informed many practices and civil

penalties against self-killing: the individual who had killed himself or herself would have no proper burial and the family would lose all their property. The condemnation of self-killing acts has been passed down throughout the centuries and still underpins the doctrines of the Roman Catholic Church, the Protestant Church, and Judaism in the twenty-first century (Ryan et al. 45).

In the twentieth and twenty-first centuries, the acceptance of practices of self-killing underwent another change. Until the end of World War II, ideas about euthanasia and assisted suicide were underpinned by Darwin's theories of evolution, especially under the guise of Social Darwinism, which was deeply linked to eugenics as well. However, the discovery of the horrific medical experiments that had taken place in the Nazi camps marked a shift in Western sensibilities. In addition, the growing secularization of traditional authority in the 1960s and 1970s granted right-to-die organizations leeway to rally around the civil rights of the terminally ill. This was also an age when the process of dying started to be prolonged due to technological advances and public debate around the autonomy of the individual re-emerged (Ryan et al. 46).

Notwithstanding, even though suicide, euthanasia and assisted dying have historically been perceived on the same moral grounds, more recently, the religious and the secular society's viewpoints have somewhat diverged. Medicine and secular law have shown more leniency towards self-killing (Ryan et al. 45). On their part, contemporary right-to-die movements have founded their claims on the dignity of the terminally-ill individual.

The Birth of Biopower and Biopolitics

Foucault's concepts of biopower and biopolitics have been used to foreground the role of institutions in the normalization of knowledge and correlate practices. In the seventeenth and eighteenth centuries, Foucault argues, political power began to exercise a specific kind of power, *biopower*, that targeted the human body. This *anatomo-politics* depended on a range of disciplinary techniques, such as the spatial distribution of individual bodies and organization of fields of visibility as well as the control over the bodies through exercise. In the second part of the eighteenth century, biopower expanded its scope of action from disciplinary to non-disciplinary technologies of power which, instead of controlling man-as-body, focused on controlling man-as-species (Foucault 243). The State arrogated itself the right to

control biological processes that affected the population as a whole, such as birth, reproduction, illness, and death. Consequently, from the nineteenth century onwards, political power is to be acknowledged the main regulator of biological processes such as fertility, birth, or death insofar as it has developed technologies of power, or a *biopolitics* of the population, meant to control those processes.

Even though biopolitics targets the "population as political problem," Foucault also saw it as a scientific problem (245). The creation of institutions to coordinate medical care, public hygiene, and the centralization of power would underpin the development of medicine at the end of the eighteenth century. This also implied the normalization of medical knowledge (244). In other words, medical discourse started to settle the limits of "normality," which, in turn, became fundamental to the disciplinary techniques of biopower: the "medical gaze" monitored and regulated the body and, therefore, aimed at controlling and transforming human life itself (Ryan et al. 45).

Regarding the processes of illness and death, in particular, Foucault writes that at the end of the eighteenth century, concerns around health issues no longer focused on illness as epidemics but on prolonged illnesses, which "sapped the population's strength, shortened the working week, wasted energy, and cost money, both because they led to a fall in production and because treating them was expensive" (Foucault 243-244). Illness and death merge into each other and become permanent threats to productive forces, hence to the emerging capitalist society. In fact, according to Foucault, biopower and capitalism cannot be understood separately since they depend on each other (Ryan et al. 43).

Assisted-dying Today

In contemporary Western societies, end-of-life practices have relied more on curative treatments than on palliative care or assisted dying practices. In fact, the legalization of intentional practices such as euthanasia and assisted-suicide is still controversial in many countries, while a few have already legalized them under specific circumstances. This may lead us to think that, in twenty-first-century Europe, the preservation of life and the intrinsic value of human beings informs current medical and political paradigms, which apparently contradicts the previous idea that someone's life is worth keeping as long as she or he is productive.

Foucault's analysis was deeply grounded in historical events that took place in the eighteenth and nineteenth centuries, therefore one should be careful about the trans-historical application of the concepts of biopower and biopolitics. However, this does not mean that they cannot be used as analytical tools to assess contemporary regulations and practices concerning life, death, and illness. In fact, it has been argued that the concepts of biopower and biopolitics have taken new forms in Western countries, and its consequences may not always be nefarious (Rabinow and Rose 6-7). Foucault himself suggested that "the great overall regulations that proliferated throughout the nineteenth century [...] are also found at the sub-State level, in a whole series of sub-State institutes such as medical institutions, welfare funds, insurance, and so on" (qtd. in Rabinow and Rose 7). In other words, power is often not directly exercised by the state, but it is allocated to subordinate institutions that decide over life and death.

One should not forget the role of bioethics both in the reiteration as in the questioning of laws. Laws and bioethics have concomitantly shaped contemporary medical practices in the last decades. As Rabinow and Rose put it, "it is worth remembering that medicine is perhaps the oldest site where one can observe the play of truth, power and ethics in relation to the subject, and to the possibilities of a good . . . life" (7). They also foreground the "bioethical complex" underlying this relationship: medical agents still hold the power to "let die" and decide the circumstances under which it should occur. And, what is more, they are backed by medical technology and political power (Rabinow and Rose 13).

Rabinow and Rose also observe that Western liberal societies have been forging new forms of individualization and autonomy grounded on the rights to "health, life and the pursuit of happiness that is increasingly understood in corporeal and vital terms" (17). Other theorists have also emphasized how, in the last decades, neoliberalism has come to shape its own values around personal autonomy: authority no longer emanates from the government but from the individual. Biopower has shifted to practices of self-regulation and self-discipline. Hence, the individual has become responsible for guaranteeing her or his own economically productive life. Concurrently, the governing of death has been greatly influenced by prolonged processes of dying and ageing population. To contemporary capitalist economies this represents a double burden: it not only entails the loss of productive forces but also an increase in health costs. It is not surprising, then, that debate around assisted dying practices such as euthanasia has gained new relevance (Ryan et al. 47).

Arguments in favour of pro-assisted dying have been grounded on the patient's dignity, autonomy, and power to control the "how and when" of his or her process of dying. Conversely, some of the arguments against it decry the danger of indiscriminate utilization and restrictions to the doctor's autonomy. Palliative care is presented as an alternative to assisted dying. Another argument against it claims that assisted dying practices represent an extension of the medicalization of death insofar as it is based on the normalizing power of medicine "to include suicide as a 'treatment' for terminal illness." In the end, only doctors and institutions can decide on the conditions of the treatment. In the Netherlands, for example, patients pursuing an assisted death must always follow the doctor's determinations (46). In countries where assisted dying is legal, there has been some contestation against the criteria used by doctors, institutions and the law that help define who is allowed to have access to assisted dying. For instance, in 2016, Canada legalized medically-assisted suicide for people with incurable illnesses and whose death was "reasonably foreseeable." However, the bill excluded people with mental illness. In spite of the new law, 27-year-old Adam Maier-Clayton, who suffered from Somatic Symptom Disorder, a mental disorder that caused his body to feel severe physical pain, and had been fighting for assisted suicide for years, was still excluded. On 13 April 2017, he eventually took his own life in a motel room, away from his parents and friends, in order to avoid any criminal prosecution.

Every once in a while, controversies and arguments around biopower and end-of-life decisions seem to crystallize in one single situation, as in the case of baby Charlie Gard. Charlie was born with DNA depletion syndrome, a rare condition fatal in infancy and early childhood. His doctors at Great Ormond Street Hospital in London claimed that his chances of survival were so low that, despite their best efforts, keeping Charlie on life support was not a realistic option and that their concern was to grant the baby a death in dignity. His parents thought otherwise and fought to be allowed to take him to a doctor in the United States to pursue an experimental treatment. The discord was taken to the courts, including the UK Supreme Court and the European Court of Human Rights in France, which, in the end, ruled against the parents and declared that the experimental treatment would be "futile." Consequently, the hospital was granted the right to discontinue Charlie's life support.

However, when it came to decide the circumstances under which Charlie was to die, the hospital, the judge, and the parents could not reach an agreement one more time. While the parents' final wish was to take the baby home, the hospital objected

and proposed a children's hospice as the best solution since "the risk of an unplanned and chaotic end to Charlie's life [was] an unthinkable outcome for all concerned and would rob his parents of precious last moments with him" ("Latest Statement on GOSH Patient Charlie Gard"). Public and medical opinions were deeply polarized as both parties founded their claims on different but equally valid grounds. Biopower is not always a nefarious force behind end-of-life decisions, as already pointed out. Yet Charlie's case, just like Ramon's and Adam's, has underscored that one of the greatest challenges of our time is the harmonization of its tenets with our renewed sense of autonomy.

Conclusion

Decisions concerning a good life also imply reflection on a good death. Self-killing, in particular, has been understood differently throughout the ages: from sin to crime, from crime to mental illness, and nowadays even a medical treatment (Szasz qtd. in Ryan et al. 46). According to Foucault's argument, biopower and biopolitics have shaped medical care and its normalizing gaze, making them fundamental to the control of biological processes like illness and death. End-of-life decisions, in particular, have been strictly controlled by laws, institutions, and doctors.

On the other hand, the issue of loss of personal autonomy in the face of end-of-life decisions, like euthanasia and assisted suicide, has re-emerged in the last decades. Ramon, Adam, and Charlie are only some of the people who have given a human face to the debate around the limits of the individual's autonomy in her or his process of dying.

To a great extent, the contemporary organization of medical care is still instrumental to political power in fostering the loss of autonomy of the individual facing death. However, changing conceptions of autonomy, the empowerment of individuals, and economic factors have granted leeway to the reassessment of the patient's role in the process of dying.

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[1] Film director Alejandro Aménabar recreated Sampedro's story in his film *Mar Adentro* (2004).

[2] More, a devout Catholic, was not in favor of such practices. In fact, he voices his own views on killing through Hytloday's reference to God's prohibition of self-slaughter early in the book: "God has forbidden each of us not only to take the life of another but also to take his own life" (More 22). Regardless of the method through which it is achieved, More could not accept suicide, which he considered the "wicked temptation." See *A Dialogue of Comfort Against Tribulation* (1534).