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Jean-Christophe Weber

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***Bare Life, State of Exception, Sovereign Power: are those Concepts really Useful for a Critical Appraisal of Medical Practice ?***

JC Weber

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## 1. Introduction

1.1. In *Homo Sacer*, Agamben raises medical issues beyond the case of experimentation by nazis doctors. He says that “The physician and the scientist move in the no-man’s-land into which at one point the sovereign alone could penetrate” (HS p.172 / 91). He discusses the case of brain death, “purely bare life” (ibid., p.178/94), “ransom of new life-support technology” (HS p.173/92), “no man' s land between coma and death” (ibid., p.174/92), but “ideal condition for the removal of organs” “without being liable of homicide” (ibid.,p.175/93). Already in *Means without ends* (MSF, 1995), Agamben denounced the decisive function

“of medical-scientific ideology within the system of power (...).That same drawing of naked life that, in certain circumstances, the sovereign used to be able to exact from the forms of life is now massively and daily exacted by the pseudoscientific representations of the body, illness, and health, and by the "medicalization" of ever-widening spheres of life and of individual imagination” (MSF 18-19 / 18).

Therefore, it would be interesting to test the concepts which he put in debate and linked together, -bare life, sovereign power, and state of exception-, as tools for critical analysis of contemporary medicine. I will not adress this issue in a general way, but through the magnifying glass provided by a very small field, the medical termination of pregnancy (medical TOP).

1.2. In 2003, I conducted a qualitative research on this topic in France.

At that time, the goal of the research was not biopolitics: it aimed to investigate daily practices, lived experiences of professionals in challenging situations. The case of medical TOP, especially at the latest stage of pregnancy, was regarded as an exemplary situation of the complex processes that are intertwined within decisions and health practices. Indeed, to carry out a late TOP is strictly controlled by law, is very codified by technical procedures, but it is also shaped by the subjective implication of all the actors - women or couples, *ad hoc* committee, healthcare team -, their emotions, their affects and, like any care, it is fully embedded in narratives. Late TOP raises a great number of ethical interrogations, tensions and conflicts of values. We sought to elucidate the normativity that is really at work, and

how caregivers give a meaning to what they do. The political issues were not directly addressed, but appeared clearly in the interviews.

2. For a good understanding of what will follow, I will briefly recall what TOP consists.

2.1. It is generally the result of a process whose starting point is an echographic diagnosis or an amniocentesis leading to discover malformations or chromosomal abnormalities. Medical TOP is sometimes performed at a late stage of the pregnancy, because diagnosis or prognosis were not achieved before, or because the decision making process took time. According to the law, the termination stems from the request of the duly informed pregnant woman, who must apply for the possibility of medical TOP from a referent obstetrician. The case must be discussed in the CPDP, an *ad hoc* regional committee which involves experts of many specialties. The CPDP provides an advice, in precondition of the legal certificate that allows the medical TOP if, according to the law, “the continuation of the pregnancy puts in danger the health of the woman”, or if there “is a strong probability that the unborn child suffers from a condition of a particular gravity considered to be incurable at the moment of diagnosis”.

2.2. Diagnosed fetal abnormalities are of very variable prognosis. Some malformations are incompatible with extra-uterine life. Other states are only related with a statistical risk of mental disability. Down syndrome or trisomy 21 is screened on a routine basis for any pregnancy. Medical TOP concerns as well fetuses who could live a long time as children and even as adults, than fetuses who would die quickly after birth.

2.3. Fetal death results from the induced expulsion of a nonviable fetus or from a specific act called feticide, when the pregnancy extends beyond 22 weeks. When needed, the feticide is carried out by a physician, under echography, by injection of potassium chloride -in the umbilical cord or directly in the heart- which causes death by cardiac arrest. The feticide prevents a fetus from being born alive, because after delivery its life is absolutely protected by the law.

2.4. Delivery is induced by the combination of two drugs, given in two times: *mifepristone* interrupts the resting state of the gravid uterus ; it is taken orally, under the control of a physician or a midwife; the pregnant woman goes home and comes back to the hospital two days later, for the further proceedings, which is almost entirely and exclusively carried out by midwives in the delivery room; *misoprostol* is the second drug, placed in the vagina, which induces labour. Note that delivery takes place in the delivery room, as usual.

2.5. What happens after delivery to the dead body was discussed before with the parents. Caregivers take care of the dead body : toilet, presentation to the parents, pictures, and so on. Giving a name, inscription in the Public and in the family registries, organization of funerals : there are a lot of legal dispositions that have changed in the last years. Many of

these reforms are very much in line with an increasing recognition that a real non viable child –and not a mere fetus- is born without life. This recognition is encouraged by caregivers.

3. I will return in one moment on some results of the research, but I would like to say at the outset how the thesis of Agamben would apply to this field.

3.1. Briefly, analysis of the medical TOP according to Agamben supposes three elements that are tied together: isolation of a bare life - sovereign power, extended to, or divided with, or delegated to medicine – and an act of killing without committing a murder. According to Agamben, “In modern biopolitics, sovereign is he who decides on the value or the nonvalue of life as such” (HS p.154/83). Biopolitics is then transformed into thanatopolitics and medicine takes part in the definition of the lives that deserve respect.

So one could say that the prenatal diagnostic process isolates a bare life without value which may be taken away without punishment. Medical TOP would be an approved killing starting from the sovereign determination of a life which does not deserve to live.

It should be noticed that this is the ongoing opinion of opponents to any kind of abortion. I will not discuss this point, except to say that this almost caricatural statement summarizes many of the fears expressed in the interviews, and that the agents have to fight against this representation which would make of them the strong arm of eugenics. We will see how they do, but this simple report may justify turning to Agamben for our inquiry.

3.2. Let us come now to some of the main results of our research. It is notable that each key concept delineates what appears as areas of uncertainty for caregivers, and as places of ethical issues. But giving empirical thickness to these concepts makes also possible to attenuate assertions that seem peremptory. The isolation of a bare life fits poorly with the figure of a very short prenatal life that is embedded in emotion-loaded narratives, and is inscribed in official Registries. A shared sovereignty between State and medicine fits poorly with the place left to women in the decision making process. The opportunity to take life without punishment fits poorly with the massive representation of a transgression that must be rationalized by the actors who have the hard task of dealing with such cases.

On the contrary, one could argue that the makeshift that is used by caregivers in order to bear what they are doing, is the sign that they are involved in a dramatic process that need to be attenuated. In other words, is the sign that biopolitics has clearly become thanatopolitics in a new death camp inside the maternity ward.

#### 4. The decision-making process:

The text of the law is very precise, but nevertheless organizes a fuzzy area regarding who is really responsible for the decision of TOP: the voluntary pregnant woman? The physicians and the committee which give their approval? Who really orders the state of exception, enacts the ban, allows for killing, who is really sovereign? You may notice that there is a semantic ambiguity with the french word "IMG" that is used for medical TOP. "IMG" means "medical interruption of pregnancy", whereas the law concerns a "termination of pregnancy carried out on medical grounds".

If the decision is understood as a single specific moment, it is especially the parents who are supposed to be in charge for the decision. Indeed, when professionals are directly questioned ("who makes the decision of TOP?"), most of them answer: "the parents". A few doctors who take part in the CPDP are more moderate. One specifies that "In the law, the decision clearly ultimately belongs to the CPDP, which will accept, accede to the request or not". For another doctor "The parents, who are correctly informed of the baby's condition, are best placed to make this decision. But currently in the law, the doctors constitute a parapet of this request, and it is a positive thing". This physician considers himself as the guardian of the life against the parents who claim death. As a whole, the professionals don't identify themselves as the strong arm of a thanatopolitics. They are faced with the question of whether they are still in their own role when they have to make a judgment on forms of life; even the cases of disagreement with the maternal request are judgments' on life.

When the decision is understood as a process that takes time and involves many conversations, it is hard to determine at which time and by whom the decision is taken. One could think that here we have a decision-making process that is really shared, but an opposite interpretation may be proposed: this process hides a decision that is made "without any subject". Two midwives suggest this reading when they use the indefinite pronoun: "If it is indeed an incurable anomaly, at this time, one considers the termination of pregnancy"; or : "According to the anomaly which is detected in the child, one speaks about this case, and one accepts or not a TOP".

Culpability may be a reason of decisions "without subject". In the paternalistic tradition, the physician is supposed to endorse the moral weight of the decision, because: "*There are women who already feel guilty to give birth to a disabled child, and it would be very hard to be obliged to make a decision of death*". But this physician says also: "*For me, the doctors do not have the supplement of soul that would be necessary for them to decide who can live or who may die*". Another physician tells that "*In this field, we realize, gradually, that there is an enormous induced culpability among people because they make the decision. We propose, but we do obviously what they want, and therefore, they have to take the responsibility for the decision, nevertheless*". A midwife is sorry to say that : "*It is perhaps certainly better than they decide at a given time, even if they is a little dreadful*". The existence of the CPDP is appreciated by all the actors, because it allows to reduce the burden of the responsibility:

*“That relieves”*. Therefore, it seems very hard to assume the role of the sovereign when biopolitics may turn over in thanatopolitics.

5. The second area of uncertainty relates to the rightness of the taken decision. The law states that TOP is allowed according to the severity of fetal condition. It is a field open to interpretation, and several logics confront each other : public health policy, societal pressure, medical customs, individual interests. There are many different points of view to appreciate the fetal condition. The prognosis implies a judgement on the acceptable quality of life for the child and for its family, on the futility of the post-native treatments. With Agamben one could ask : Which are the edges of Fetus Sacer? What is a life which does not deserve to live?

There is a certain consensus to perform TOP in some cases, even if they are only discovered at the latest stage of pregnancy. For example, a foetus which develops without brain, or with organ malformations incompatible with a life of more than a few days or weeks after birth. By the way, in most of these cases, a spontaneous fetal death occurs in utero, and the practical issue relates more to the moment of a possible interruption than on its rightness. But there is also an apparent consensus, and well beyond the medical profession, about Down syndrome or trisomy 21, which is routinely screened. The screening policy is directed towards one single goal: to avoid the birth of trisomic children. As a whole, the professionals agree with that, but some are reluctant to perform a feticide in such cases.

Less the anomaly is serious from a strictly medical point of view, more the consensus around a decision can prove to be difficult. All the interviewed doctors worry about the evolution of the requests that come to the CPDP, and about the evolution of the answers of CPDP, which seem to go sometimes against their own convictions. The criterion whose importance is new is the suffering anticipated by the mother or the couple in front of the birth of a disabled child, and their expected distress with respect to their future with this child. A doctor says : *“In fact, now, when a couple says to us: “but we cannot deal with, we will not be able to raise this child”, it is true that maternal distress becomes a dominant issue in the decision of CPDP (...) Really, we see that, in some cases, in some family contexts, the CPDP grants this request, therefore one slips gently of a position where it was a purely medical decision with a situation where parental autonomy appears”*.

In the book *“The fetal condition”*, Boltanski suggest that a consensus is achieved about voluntary abortion by the mean of an *“ontological manipulation”* of the fetus. This manipulation rests on a distinction established by both women and caregivers between two statutes of the fetus: the *“authentic fetus”*, already adopted by the parents before birth and considered as a future baby, and the *“tumoral fetus”*, an *“accidental embryo which will not be the subject of a life project”*. We could say, according to Agamben, that a distinction is made between fetuses either already engaged in a *bios* by parents’ words and imagination, or already reduced to *Zoe*, whose growth would obey a blind logic and who must be extracted as quickly as possible. Does this ontological manipulation occur in the case of medical TOP? Undoubtly, until the diagnosis is achieved, the fetus is still fully perceived like an authentic fetus by the parents and by caregivers. It is a wished pregnancy, an invested

baby, and considered as such by the doctors too. The diagnosis which indicates the existence of pathology comes to break out this beautiful unanimity. For many parents, the authentic fetus becomes then, and very suddenly, a tumoral fetus. But the same does not happen for medical team : the disabled fetus does not become a “tumoral fetus”, but is still a baby, a very human subject. The unborn child will not achieve its full potency of living, and will be engaged in death, but beware!, the TOP is undertaken on the principle of benevolence that governs the whole of medical practice. TOP is seen as a very exception (and not a rule of exception), in the cases of unbearable life. Therefore, it is not surprising that professionals use the expression of *prenatal euthanasia*.

6. The third zone of uncertainty relates to the killing act. When one tries to determine when the TOP actually occurs, nobody gives the same answer. In the absence of feticide, all is made to mask when, by what and by whom the fetal life is taken away. The TOP may represent “only” a delivery that is induced too early, so that it produces a stillborn baby. Thus, the question “Who practices the TOP? ” cannot be answered without a great perplexity: as a matter of fact, the process is split in several acts, at different moments, in several places, by many agents. This dubious delimitation of the very moment of TOP is also a way to reduce the responsibility for causing death. With Agamben’s words, not only there is no homicide, but nobody even committs it.

On the other hand, when a feticide is performed, death is induced at one precise time, and this moment is the most difficult one for those who achieve it. The difficulty with feticide directly related to the thought of a transgression. The legal framework seems too weak to provide always legitimacy. This is also a good reason to represent TOP as a prenatal euthanasia. Late TOP is regarded as the inevitable loss of a child too sick to be healed, a killing by compassion in order to avoid later sufferings.

A killing by compassion is not fully consistent with isolating a bare life that can be taken away without transgression. Moreover, after delivery, the dead body is the subject of ritualized practices aiming at underlining its humanity. These practices don’t meet what may be expected in the case of a mere dead *zoe*. The actions of caregivers are on this point eloquent: they take the dead baby in their arms, they speak to him, they dress him, they take pictures, and they deal with him as they would deal with a living baby. Sometimes parents are reluctant to these rites, but they are encouraged to work up a perinatal bereavement, as parents who have lost spontaneously their child. Some professionals consider that the humanization of the fetus becomes artificial : every effort is made to restore the figure of a child whose death stems from disease, whereas this child has already been killed. The transformation of the killed fetus into a dead baby may contribute to hide that death was deliberately carried out by caregivers and required by parents.

## 7. Conclusion

The figure of a prenatal euthanasia and the rites which follow delivery are two constructions that aim making livable what remains a very difficult event both for parents and for

professionals. One may consider that we are far from the violence of the camp, to which Agamben compares some medical places. But in the case of the prenatal screening of Down syndrome, these constructions look flawed in the eyes of many professionals. The societal and political goal of prevention of the birth of disabled children appears very different from a case-by-case approach and has been depicted by some authors as an extreme form of utilitarian logic which is accompanied by injustice and discrimination, by disqualification of disabled people, or like an eugenistic thanatopolitics that undermines the freedom of pregnant women. One could then be tempted to connect medical TOP to the persistence of a sovereign power of the State that would eliminate the undesirable ones. It would be therefore a kind of racism as Foucault noted in the lessons of "*Il faut défendre la société*". The "the old sovereign right to kill", is exerted on biological criteria (Foucault, p.227). In *What remains of Auschwitz*, Agamben agrees with Foucault on this point.

In my opinion, biopolitics is not a homogeneous dispositive. Valorization of bare life is still in tension with valorization of good life. Life is challenged with societal acceptance of disability. The balance is not only in the hands of a sovereign power that may be shared between the state and health professionals. The field of TOP is also the result of social movements which contributed to impose the evolution of law, and the place that is reserved for the words of the mothers limits any sovereign power. If one considers that the only sovereign should be the pregnant woman, that the qualification of a fetal life not deserving to be lived can be only one subjective judgment of the mother, then one should accept that the prenatal life remains outside the *polis*, belongs to the *oikos*, and that it is no more a matter of biopolitics. Unless one means that the ultimate level of biopolitics is a fully incorporated biopolitics, and that the sovereign power "of making die" is delegated to the individuals themselves. Agamben claims that "the sovereignty of the individual over his own existence" is an implicit "politicization" of life (HS 150/81). One could argue that if everything that goes around life is politics, therefore the game is already lost : the biopower precludes any form of resistance.

The fact is that the power of judging the life exists *de facto*, even if the real place where this power is exerted is not so clear today. The development of biological devices and medical imaging in the prenatal diagnosis supports the production of standards of conformity, so that the decisions taken by CPDP and informed women look like a real determination of the worthy and unworthy forms of life. The only fact that these decisions are made in a medical setting maintains the idea that there are nonindividual standards making it possible to distinguish between the good life and the life which does not deserve to be lived. But does this fact entail that our world has been converted in a camp? Analyzing the field of medical practices with Agamben's view on biopolitics appears tempting but radical, or perhaps even tempting by its radicality. Except adopting the whole of his system in its internal coherence, we remain a little disappointed to appreciate the complexity of the situations and their nuances, which are echoed in the hesitations of the health practitioners. The couple bare life/sovereign power is somewhat excessive, isn't it? I'm looking forward to your critics and your questions.