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## **GIVING VOICE TO THE PATIENT IN VEGETATIVE STATE: BIOPOLITICAL INTERSECTIONS OF DISCOURSES ON HUMAN LIFE AND FEMALE BODY**

### **ABSTRACT**

This article focuses on media representation of two cases of young women diagnosed with vegetative state for a prolonged period of time, the North-American Terri Schiavo and the Italian Eluana Englaro, and on how their bodies became signifiers of moral panic, embodying a threat to prevalent social norms through the possibility, which came to be concretised in both cases, of their being disconnected from the feeding tubes that maintained them alive. The bodies of these two patients, with “no evidence of awareness of self or environment and an inability to interact with others” (Multi-Society Task Force on PVS, 1994, p. 1500), and reduced to basic biological functions, such as breathing with preservation of sleep-wake cycles, became the site of conflicting discourses on life, namely on definitions of life, the kind of life that deserves to be kept alive, the role of political and social institutions in the preservation or elimination of such life, and, ultimately, on what it means to be human. Textual analysis of Portuguese online news on the Schiavo and Englaro cases will focus on the variety of biopolitical factions that articulate their own views on the legitimacy of life and the conditions of such legitimacy. These discourses, although not strictly gender-oriented, lend themselves to gendered readings, not least because these two cases involving young women were deemed as particularly newsworthy in the media, to the detriment of many other such cases that exist, involving individuals who are neither young nor women.

### **KEYWORDS**

Vegetative states; biopower; ethics; gender; voice

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## **1. INTRODUCTION: THE VOICELESS FEMALE MARTYR**

This article focuses on media representation of two cases of young women diagnosed with vegetative state for a prolonged period of time, the

North-American Terri Schiavo and the Italian Eluana Englaro, and on how their bodies became signifiers of moral panic, embodying a threat to prevalent social norms through the possibility, which came to be concretised in both cases, of their being literally disconnected from the feeding tubes that maintained them alive. The concept of moral panic is usually connected to fear of criminal deviance, or a threat to social order, frequently fostered by the media (Cohen, 1972; Krinsky, 2013; Young, 1971). Likewise, as regards the issue at hand, there is fear that machine disconnection correspond to a form of deviance due to ending a life that is organically alive, despite no longer being equated to 'good life'.

More specifically, the perceived threat to social order is that human intervention, through the disconnection of a feeding tube, might be sealing the fate of patients who, despite having, apparently, severely impaired cognitive functions, are still capable of carrying out some vegetative physiological functions with life-support treatment. The fact that this issue is seen as managed by either the courts on the one hand or by the State, in both cases, means that the threat it represents may be subject to social and political control. In the process, the voice of other parties in the media, such as family members, involved in the case are ignored in favour of the traditional institutions that regulate biopower on a macro level. By biopower we mean the regulation of "a set of processes", implemented from the late eighteenth century onwards, relating to "the ratio of births to deaths, the rate of reproduction, the fertility of a population", "the mortality rate, longevity and so on" (Foucault, 2003, p. 243). Lastly, the Schiavo and Englaro cases invite ethical self-formation to the extent that both imply the necessity to rethink ethics in light of the distinction between human life and inhuman survival and the ventriloquisation of a (female) body deprived of agency.

Marie Theresa Schiavo was diagnosed with vegetative state in 1990, after a cardiac arrest at the age of 26, and was in that condition until 2005 when the life-sustaining treatment was withdrawn. Similarly, Eluana Englaro was diagnosed with vegetative state in 1992 at the age of 21, as a result of a car accident, and was in that condition until 2009 when the life-sustaining treatment was withdrawn. Both end-of-life decisions were made in a context of strong litigation and of intervention of the high representatives of the State, George W. Bush in the Schiavo case and Silvio Berlusconi in the case of Englaro. The bodies of these two patients, with "no evidence of awareness of self or environment and an inability to interact with others" (Multi-Society Task Force on PVS, 1994, p. 1500), and reduced to basic biological functions, such as breathing with preservation of sleep-wake cycles,

became the site of conflicting discourses on life, namely on definitions of life, the kind of life that deserves to be kept alive, the role of political and social institutions in the preservation or elimination of such life, and, ultimately, on what it means to be human.

We want to argue that, in these two particular cases, such debates were inextricably linked to discourses on gender, resuscitating a particular Christian iconography on the suffering of the voiceless female martyr, who through divine intervention managed to transcend her 'nature' and thus temporarily "gain the right to speak as temporary "prophet[s]" (Vance, 2000, p. 92). Indeed, where in the case of the female martyr faith implies a choice that wills absolute passivity to the will of God, implying issues of self-sacrifice and self-willed martyrdom which may connote both narcissistic gratification as well as masochistic humiliation (Blum, 1991, p. 444), in these particular cases being reduced to basic corporeal functions lends these women to complete colonisation of will by conflictual discourses of biopower.

These women are therefore the product of modernity, in that they are conditioned by the affordances of a technology in the foucauldian sense, translating as "a practical rationality governed by a conscious aim" (Foucault, 1984, pp. 255-256), which takes the governmentality of life as its object and its objective. In other words, the aim of managing and controlling the health and life of citizens becomes indissociable from a biopolitical project that accompanied the rise and consolidation of the idea of the modern State.

For Agamben, the concentration camp is metonymical for the political space of modernity, which opens "when the state of exception becomes the rule", operating outside the realm of the law, or community, where *every* citizen is potentially reduced to naked life. Under the state of exception, the living body becomes "the rule and criterion of its own application" (Agamben, 1998, p. 173), meaning that the living body becomes an end unto itself, transcending the rule of law. In such situations, the ethical ceases to exist, because life is considered in absolutist terms and the difference separating human life from inhuman survival is not taken into account.

The paradox of the camp lies, then, in its 'inhabitants' finding themselves "stripped of every political status and wholly reduced to bare life", while simultaneously inhabiting 'the most absolute political space ever to have been realised, in which power confronts nothing but pure life, without any mediation' (Agamben, 1998, p. 171). The deprivation of political status, the loss of voice, thus provides the ideal space for the exercise of power "to make live and to let die" (Foucault, 2003, p. 241). We argue here that the vegetative condition in which Terri Schiavo and Eluana Englaro found

themselves constitutes one such site in which discursive regimes of truth vie for such power over purely biological life.

On the basis of textual analysis of online versions of Portuguese newspapers, we will try to understand the intricate biopolitical exercise, on the part of the legislative, executive, judicial, familial and ecclesiastical powers involved, to ventriloquise the voices of both Schiavo and Englaro, often conferring on the latter desires that emanated from particular understandings of the most simple physiological manifestations as signalling something other than simple, pure 'naked life'.

## 2. THE BODY AS PRISON: BEING WITHOUT VOICE

Contemporary biopolitics centres not on death but on 'life' – that is to say, it is organized around dilemmas concerning human vitality: human rights to life (a dignified life, a quality of life), the equality of all humans as particular kinds of living creatures (human rights), the value of life, the future of life, and what can be done to the lives of some to facilitate the lives of others (pre-implantation genetic diagnosis, stem cells, organ transplants, donations of body parts). (Rose, 2007, in Rose, 2013, p. 4)

While the 'psy' sciences influenced individuals' understandings of self during the 20<sup>th</sup> century, becoming crucial to the way they lived their lives as well as to their governance by authorities (Rose, 1999, p. 92), towards the end of the 20<sup>th</sup> century another ethic, that of biology, has become salient, connected to the belief that "key features of our identity as persons are (were) grounded in the flesh" (Rose, 2013, p. 7).

This is additionally interesting from a gendered perspective because of difference feminism's idealisation of the female body as articulating an autonomous biological essence external to any socio-cultural mediation (Plaza, 1978, p. 7). Irigaray, for instance, points to the realm of the symbolic order that prevails in the Western context as condemning woman to mutism. As such, she attempts to think up a form of writing that mirrors the female body as referent, in its materiality, so as to emancipate woman from the straightjacket of linearity which prevents her from expressing "concrete and embodied experience" (Giardini, 2003, p. 14). The female body is thus the source that inspires Irigaray, Kristeva or Cixous to write back against 'speechlessness'.

Paradoxically, in the two cases that we are analysing here, the body, reduced to utter passivity, is, by force of circumstance, the only instrument that could be seen as speaking for itself: it is apparently not capable of being symbolised by its owners in its materiality, contrary to what Cixous attempts to achieve by creating an *écriture féminine* that “allows feminine desire, the language of the body, to reconstitute expression as a revolutionary movement against the masculine rhetorical structure that has defined language over time”, thus resisting phallogentrism (Alexander, 2011, p. 1). The owners of these bodies in vegetative state have no choice but ‘to let’ others speak in their place and be subjected to the materiality of a phallogentric ‘tube-rape’ (Beyerstein, 2005, in Protevi, 2009, p. 127) (the percutaneous feeding tube of artificial hydration and nutrition).

Thus, while for difference feminists being grounded in flesh, or naked life, is celebratory due to drawing women closer to a ‘self-directed’ definition of identity (Stone, 2004, p. 10), for Terri Schiavo and Eluana Englaro being reduced to naked life is a tragedy. We would argue that these latter cases are particularly disturbing because they shake certain conventions that some circles of Western academia have come to accept regarding the emancipatory potential of the body, not so much from a difference feminist but more from a postfeminist perspective. The latter seeks to engage with traditional sexualised female stereotypes in a playful, light-hearted manner, in the attempt to define a ‘new subjective space for women’ that reconciles femininity with feminism. Postfeminist subjectivity involves the staging of a sexualised feminine body that reconstructs feminist ‘autonomy and agency’ so as to transform women’s past sexual objectification into a subjectification (Genz, 2006, pp. 344-345) that is willful and not passive.

Reduced to *zōe*, natural life, the vegetative body is a body that matters (Butler, 1993) not in a postmodern performative sense that actively wills experimentation with different identities, but rather as reified materiality. Nor is this materiality that of Donna Haraway’s cyborg, which breaks down the human/animal or organism/machine dichotomies (Teyssot, 2005, p. 78) in the search for an emancipatory post-human figure that is capable of breaking away from the constrictions of both gender and sex. While the vegetative body reduced to *zōe* is indeed animalised in its pure systemic physiological functions, it simultaneously does not transcend animality through technology: rather, technology extends and perpetuates the vegetative’s body animality, and it is only with the switching off of the ‘machine’ that the body emancipates itself from itself. Contrary to the vegetative patient who can be characterised as void of subjectivity, Haraway’s

hybrid ‘inappropriate/d other’ enjoys “the relative freedom of movement of the subjects-to-be regarding a position of otherness that they neither fully occupy nor completely adjust to” without losing the ‘power of agency’ (Prins, 1995, p. 357).

### 3. TEXTUAL ANALYSIS OF ONLINE NEWS: THE SUBJECT SOUS RASURE

The bodies of Schiavo and Englaro are indeed erased of any mark of subjectivity in their representations in the media, and either one is often described as ‘a woman in a vegetative state’, reduced to a medical condition. Erasure is a given fact in Portuguese online news coverage on these cases, allowing, in the Schiavo case, for a battle over biopower among her parents, her husband, the courts, the governor of Florida, the North-American Parliament and Government and, in the Englaro case, for a biopolitical dispute among the Italian Government, the Italian Presidency, the courts and the patient’s father (Fernandes, unpublished).

The online versions of the Portuguese newspapers *Correio da Manhã* (CM), *Diário de Notícias* (DN), *Expresso*, *Jornal de Notícias* (JN) and *Público* focused on evidence or not of consciousness in the description of the mind and body of these two women, equating any sign of consciousness with vitality. In short, evidence of consciousness was used by the media as a discursive strategy to justify the need for the maintenance of life, often using illocutory techniques to intensify the suffering resulting from a slow, agonising death from hunger and thirst (when there are doubts about the capacity of this type of patient to experience or not those sensations (McCullagh, 2004, pp. 231-232).

Online news description of the two cases, illustrated in the examples below, privilege voluntary movement capabilities as indicative of consciousness. In both cases, there is an attempt to delegitimise the judicial biopolitical decision to terminate artificial hydration and alimentation:

Based on changes in facial expression, her [Schiavo’s] parents believed in recovery. (JN: 23-03-2005)

... her [Shiavo’s] parents, supported by various Catholic organisations, affirmed that Terri is conscious. (JN: 22-03-2005)

Terri Schiavo’s parents argue that their daughter is sensitive to stimuli. (JN: 31-03-2005)

Terri Schiavo's parents and sister believe that their family member's health can improve, based on the reactions that the patient presents. (*Público*: 18-03-2005)

It is a defeat for Eluana, a young woman who lives, who breathes autonomously, who wakes up and sleeps, who has life', affirmed the president of the Pontifical Academy for Life, Rino Fisichella, to the Vatican Radio. (*DN*: 15-11-2008)

Description of the sedation of both Schiavo and Englaro draws attention to the fact that the classification of a patient as being in a vegetative state preserves a legitimate doubt as to whether or not the capacity to feel pain and experience suffering denotes the existence of consciousness. In both cases, the Catholic Church played an active role in campaigning for the maintenance of life-sustaining treatment of the two women on the basis of the idea that their capacity to feel pain implied that they were alive:

"Her [Schiavo's] pain is that of humanity's, the slow and terrible agony of Terri is today the agony of the sentiment of God, the agony of His love which envelops those who are most frail," writes the *L'Osservatore Romano*, the Vatican official newspaper. (*DN*: 22-03-2005)

In the *Corriere della Sera*, one reads: "The media campaign of the Catholic Church changed the perception of the agony of the young woman [Englaro]". (*Público*: 8-02-2009)

Last Friday the doctors stopped feeding and hydrating her [Englaro], only giving her sedatives so as to not let her suffer. (*Expresso*: 9-02-2009)

However, the fact that Schiavo was not sedated at the time of the withdrawal of the life-support treatment (Fins, Illes, Bernat, Hirsch, Laureys, & Murphy, 2008) illustrates that the expression of doubt as regards the capacity of a vegetative patient to feel pain was less of an issue at the time of the Schiavo than the Englaro case, indicating that certainties about the vegetative state tend to erode with new investigations.

Newspaper articles emphasise that the patients' capacity to feel both pain and pleasure are the target of an attempt at silencing by the courts, and they seek evidence in physical and physiological manifestations to buttress the belief that such patients should not be 'disconnected' from life.

Schiavo – who had had Holy Communion during Easter with a drop of wine –... . (CM: 29-03-2005)

Eight days ago, when the feeding tube was withdrawn from Terri, she emitted a few sounds, which her parents interpreted as words. According to the [their] petition, such sounds meant “I want to live”, and, as such, a request was presented at court to authorise the administration of liquids so as to verify that possibility. (JN: 27-03-2005)

The father of the patient, Bob Schindler, guaranteed yesterday that his daughter reacted when he gave her [Schiavo] the news. “I told her that if she was ready, she should run down for lunch, and she gave me a big smile,” affirmed Bob. (CM: 22-03-2005)

More than scientific, the frequent descriptions of the patients’ body, pointing to fatigue, hunger, thirst, dry mouth, scaling skin, are essentially biopolitical in that they signal a camp where both life and the will to live is disputed:

A woman in a Miami hospital is about to die from hunger and thirst. This is the slow death of a person, not of a vegetable, and the world assists, impotently, through TV and newspapers. (*L’Osservatore Romano*, the Vatican official newspaper, quoted in JN: 22-03-2005)

The patient received Holy Communion, last Sunday, under the authorisation of her husband, Michael Schiavo. Nevertheless, the patient could not swallow the host, due to having a very dry mouth. She was then given a drop of consecrated wine during the mass that was celebrated in the centre of intensive care for terminally ill patients. (JN: 29-03-2005).

On the thirteenth day of hunger and thirst, Theresa Marie Schiavo died. (DN: 01-04-2005)

The minister for Reform, Umberto Bossi, reacted saying that a person [Englaro] should not be “left to die from hunger and from thirst”. (*Público*: 10-02-2009)

The person responsible for the Pontifical Council for Health Care, Cardinal Lozano Barragán, equated the ruling

by the Italian Supreme Court with the condemnation of Eluana “to a monstrous end”, a “homicide, in which she will be left to die from hunger and thirst”. (*DN*: 15-11-2009)

Despite the possibility of the necessity of sedation, linked to an irreducible ‘biological limitation’ (Multi-Society Task Force on PVS, 1994, p. 1501) that limits what can effectively be said about the consciousness of another person, the medical sources in both the Schiavo and Englaro cases are those portrayed by newspapers as most radical in defining the vegetative state:

“To family and friends, and to less experienced doctors and nurses, patients in persistent vegetative states seem quite normal,” explains Dr. Ronald Cranford, specialist in Neurology and Bioethics. “Their eyes are open and they move during periods of wakefulness. There can be spontaneous movements of arms and legs, and sometimes such patients seem to smile, laugh, make sounds and adopt other facial expressions,” explains the doctor, accentuating, nevertheless, that all these signs are simple automatic reflexes and neither expressions of consciousness nor will. (*CM*: 22-03-2005)

The neurologists contracted by her husband testify that Terri Schiavo is in a permanent vegetative state, but not brain-dead. She cannot think, speak or react to anything close-by. She presents non-cognitive functions such as breathing, circulation and blinking. (*Público*: 30-03-2005)

“The vegetative patient does not have consciousness of self nor relational life,” explains to *Público* the specialist in internal medicine, Luís Campos. “S/he does not establish communication”. (*Público*: 11-02-2009)

According to physicians, Englaro died, in fact, on the day of the accident, when she lost all her faculties. (*DN*: 9-02-2009) ... cognitively, she does not exist; she does not feel. (Oncologist Ferraz Gonçalves from the Oporto Portuguese Institute of Oncology, *CM*: 15-02-2009)

The medical descriptions of the patients erode them ontologically, reducing their bodies to bare life and to a condition of being “static and undead” (Reno, 2014, p. 22), “faceless and voiceless” (Žižek, 2005, p. 160) and “deprived of the capacity to die” (Žižek, 2008, p. 9).

The diagnosis itself has an effect beyond the bed of the patient, due to defining his biopolitical condition. This bare life enters into political calculus by becoming an object of biopolitical decision over whether life should be maintained and what kind of life should be preserved. Eluana's father, Beppino Englaro, declared: "she is only a body in the hands of those who assist her" (*DN*: 15-11-2008). And this is indeed what one regime of truth maintains, that the patient in vegetative state has already died, continuing to exist 'only' as a 'body'.

Despite all the quotes above essentially reducing the patient's vegetative state to bare life, none more so than then Italian prime-minister Silvio Berlusconi's description of Englaro as a 'young woman' still "capable of having babies" (*DN*: 9-02-2009) draws attention to what, in his perspective, Englaro maintains as crucial to her essence, that of the female capacity to produce and bear children, independently or not of the fact of being in possession of cognitive functions. What is salient, then, in the latter quote is the fact that this woman is still capable of acting as a vessel of life, bringing forth new life into the world and, as such, her being artificially kept alive is fully justified. Berlusconi thus emphasises her sexual, rather than her gendered identity in an urge to reinforce the body's biological life as the object and objective of modern biopolitics, stripping that very body of its gendered political status in the process.

#### 4. CONCLUSION: ACT OF CARE OR DEFICIT OF AGENCY?

Because the vegetative patient's life is bare, lived out crudely, her – either Schivo or Englaro's – voice results from a biopolitical decision that is based on the voice of legal power instead of her body's manifestations. The biopolitical decision to end the life of these patients shows that they are spoken for by a variety of biopolitical factions that articulate their own views on the legitimacy of life and the conditions of such legitimacy. These discourses, although not strictly gender-oriented, lend themselves to gendered readings, not least because these two cases involving young women were deemed as particularly newsworthy in the media, to the detriment of many other such cases that exist, involving individuals who are neither young nor women.

The news-value of 'personalisation' has led the newspapers analysed to filter information on vegetative states through the lens of these two individuals, taking recourse in a "human interest" frame' which, by eliding contextual differences and particularities, draws attention away from more

profound political issues (Wright, 2012, p. 291). The tendency towards personalisation of such cases in the media contrasts with the rejection by the North-American and Italian Governments of the wishes that these *particular* patients had expressed in the past of not being artificially fed in similar medical conditions, thus erasing the voice of individual, subjective will in the decision of euthanasia.

This refusal to engage with these patients' voice prior to the latter having lost consciousness reduces them to being the object of an 'ethic of care' that revolves around their complete dependency, which in turn naturalises the self-sacrifice of those who 'care'. In the case of Schiavo, the North-American Government attended to the appeals of the patient's parents to 'save' their daughter from the courts, and the Portuguese news pieces analysed depict this appeal as a legitimate act of care. Such acts of care efface the association of care with 'institutional confinement, limited social engagement, partial citizenship, disempowerment and exclusion', as well as the fact that the recipients of an act of care 'are ontologically doomed to a deficit of agency', thereby living "'tragic" lives' (Hughes, McKie, Hopkins & Watson, 2005, p. 261). Independently of sex or social status, objects of care are represented as the 'feminine other' within the masculine imaginary (Hughes *et al.*, 2005, p. 262) that distinguishes the mainstream journalistic context, and it is thus not surprising that the gendered aspect of these two particular cases may have contributed to their newsworthiness. In effect, as a woman, Schiavo was not allowed to abandon, even in vegetative state, her carers, with her parents accepting the possibility of amputation of their daughter's four limbs if necessary for her survival.

Additionally, the vegetative state of Schiavo had resulted from cardiac arrest, caused by a potassium imbalance and leading to brain damage due to lack of oxygen, brought about by a binge-eating disorder (Hansen, 2012, p. 99). As such, by having been unable to resist a social context that seeks to fit women's body into 'normalised' parameters, Schiavo may be considered as ventriloquised before suffering brain injury, having this very ventriloquisation resulted in her vegetative state. Schiavo was, moreover, undergoing assisted reproduction treatment before occurrence of the acute brain lesion. The fact that her obstetrician failed to diagnose her bulimic disorder while subjecting her to fertility treatment may have contributed to Schiavo's cardiac arrest, leading her husband to file – and win – two lawsuits for medical malpractice (Hook & Mueller, 2005, p. 1450; Wolfson, 2005, pp. 41-42).

It can hence be suggested that this physician, alongside Schiavo's husband and parents failed to acknowledge the importance of the

ventriloquisation over Schiavo's body that caused her to remain silent concerning her bulimic eating disorder. This silence is again witnessed in relation to her fertility treatment, the latter which, as "arbiter[s] of values and standards relating to women's reproduction and motherhood" (Crowe, in Nordqvist, 2008, p. 278), treated the specificity of Schiavo's body as invisible in the urge to exert over it a normalising, disciplinary technology of control. Already in a vegetative state, Eluana Englaro is further subjected to ventriloquisation by discourses of reproduction on the part of prime-minister Berlusconi (*DN*: 9-02-2009), who singles out the patient's 'normalising' capacity to conceive as placing her on the side of 'life', understood as living 'nature', as opposed to the technological, or the artificial (Nordqvist, 2008, p. 279), perceived as Artificial Hydration and Alimentation (AHA). The ethics of care and its ontological destitution of agency, the personalisation of gendered news value and the attempt at ventriloquising voiceless patients thus intersect at particular 'nodes' of journalistic discourse, revealing that the vegetative state is indeed a topic that deserves to be addressed in gender studies.

The fact that the cases here analysed hark back to certain female stereotypes, linked to silence, passivity and suffering, which are abundant in various cultures, make them particularly disturbing. This is compounded by the objectification of the body which, contrary to most critiques of objectification, does not exude erotic vitality but rather the sadism or masochism of *thanatos*, the death drive. This body symbolises the hybridisation of human life and inhuman survival, of life and death and, as such, is a virtual space of possibility that begs for political action to be taken in its regard. Such action reveals itself as particularly difficult due to hybridisation being susceptible to multiple readings and ventriloquisations, many of which defy the biopolitical logic. Ventriloquisation can be an act of responsibility, the radically ethical capacity to make 'the decision of the other in me' (Derrida, 2005, pp. 128-129). The multiple voices that speak for Schiavo and Englaro in the polis (medical, political, juridical, familial, scholarly, religious and journalistic, among others) seek to take charge of this responsibility, being represented in the Portuguese press as vying for one of the polarities of biopolitical institutionality, that of either crudely killing or obliging to live, contributing, in the process, to frame the termination of life-sustaining treatment as a threat to the socially prevalent moral order.

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