



Anarlf meeting

Consequences of brain damage in the public debate regarding the end of life. The mediatic prism: A reflection of reality? ☆,☆☆



Conséquences de la cérébrolésion sur le débat sociétal sur la fin de vie. Le prisme médiatique : un reflet de la réalité de terrain ?

B. Devalois

Service de médecine palliative, centre hospitalier René-Dubos, 6, boulevard de l'Île-de-France, 95300 Pontoise, France

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ABSTRACT

For the last 20 years or so, conflicts on life-support have become the object of widespread media coverage. By focusing public opinion on the alleged physicians' unreasonable obstinacy, these publicized cases impact social debates on life-support. By these, they justify claims for the legalization of assisted suicide, specifically the practice of termination of life by lethal injection. Via a conducted survey of the various caretakers and families involved in this type of situation, we propose an analysis based on the different forms of unreasonable obstinacy. The reasonable or unreasonable nature of treatments can often be perceived differently by physicians, caretakers and families. At least 6 unreasonable obstinacy cases can be brought to light. Publicized cases always involve a conflict between the physicians in charge and the families who view the situation as unreasonable. Nonetheless, evidence shows that in these situations, the roles are often reversed, and the families are the ones demanding the use of unreasonable care. A typical example of this is a recent case that became the object of legal proceedings in France. As it turns out, the publicized filter does not reflect the true reality of cases involving unreasonable care. Specific procedures could aid in notifying the existence of such situations. The role of health care professionals (excluding physicians) appears to play an essential part in preventing these situations from happening.

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R É S U M É

Depuis une vingtaine d'années, des situations conflictuelles de maintien artificiel en vie de patients cérébrolésés, ont fait l'objet d'une forte exposition médiatique. En focalisant l'attention de l'opinion publique sur l'obstination déraisonnable dont feraient preuve les médecins, ces cas médiatiques influent sur les débats sociétaux concernant la fin de vie. Ils servent à justifier les revendications de légalisation des pratiques de mort médicalement assistée, notamment par des injections létales. À partir d'une enquête auprès de différents acteurs de soins et de familles impliquées dans ce type de situation, une analyse des différents types d'obstination déraisonnable est proposée. Le caractère raisonnable ou non des soins, est souvent ressenti différemment par les médecins, les soignants non médecin et les familles. Au moins 6 situations d'obstination déraisonnables potentielles sont ainsi mises en évidence. Les situations médiatiques portent toujours sur une opposition entre des médecins et des familles qui considèrent la situation comme déraisonnables. Cependant, les témoignages recueillis évoquent surtout des situations inverses, où ce sont les familles qui exigent des soins déraisonnables. Une récente affaire ayant fait l'objet d'une procédure juridique en France en est un exemple typique. Au total, le prisme médiatique n'offre pas un reflet fidèle de la réalité des

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E-mail address: bernard.devalois@gmail.com

situations de soins déraisonnables. Des procédures spécifiques pourraient permettre de signaler ces situations. Le rôle des professionnels de santé non médecins apparaît également essentiel pour les prévenir.

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1. Introduction

In the context of societal debate concerning the end of life approach these last few years, different cases involving brain damaged patients have attracted both the public opinion and the media's attention in France, as well as in Europe and in the United States. These mediatised cases often caricaturise the irrational obstinacy implemented by the medical profession, and the fight of families simply desiring a peaceful, dignified death for their loved one, far from the aggressive and invasive treatments instilled. During a mission for the ONFV (Observatoire National de la Fin de Vie – National End-of-Life Observatory) concerning medical futilities, the reality of the situation was studied and put into perspective with regards to the potentially deforming media prism [1]. In the present paper, we will use the term “altered conscious state” (ACS) to design chronic situations with alteration or suppression of consciousness in relations to brain damage (chronic vegetative state or minimally conscious state) [2].

2. Tragic mediatised situations

In 1990, in the United States, Terri Schiavo was victim of a prolonged heart attack, leading to an ACS. Eight years later, her husband asked for artificial feeding to be stopped. Her parents, fundamental Catholics, were firmly opposed. At the end of a long conflict, widely covered by the media, and various legal and political events, she passed away in 2005 following the cessation of her artificial hydration and nutrition (AHN) considered as an artificial life-sustaining treatment [3]. The plot of the Schiavo case was parodied in an episode of the American adult animated sitcom “SouthPark” that was broadcast just days before her death (Best Friends Forever, Season 9, Episode 4).

During the Hillsborough riots of 1989 (UK), “Tony” Bland suffered crushed ribs and two punctured lungs, causing prolonged cerebral hypoxia. Following many months of ACS, his doctor, with the support of his family, applied to British justice for permission to withdraw all life-prolonging treatment (including AHN). After a long and complex procedure, the House of Lords (supreme authority of the English justice) authorized cessation of treatment. In 1993, T. Bland passed away, following the procedures of this decision [4]. This case has influenced the adoption, in 2005, of the Mental Capacity Act, which still today governs these issues in England.

Eluana Englaro, an Italian woman, remained on ACS for several years, following a car accident in 1992. From 1999 onwards, her father, reflecting the will of his daughter to not be kept alive artificially, fought against the doctors and the judicial system, in order to halt the ongoing treatments. In 2007, the Court of Cassation awarded him the case. The Court's decision was met with political and religious debate. In 2009, Eluana was moved to a nursing home that consented to end her AHN. She passed away a few days later, despite many attempts to hinder this decision (from S. Berlusconi as the Italian prime minister, and head of the College of physicians and senior officials of the Vatican) [5]. Her story inspired Bellochio's 2012 film, “Dormant Beauty”.

In France, two more instances involving brain injuries followed the Vincent Humbert case [6] and received widespread media coverage: the Pierra and the Koffel cases. During the mission

studying medical futilities in France for the ONFV, in 2011, both families were met in their respective homes, in an effort to better understand what they may have been through in the phase preceding the death of their loved ones.

In 1998, Herve Pierra committed suicide by hanging, in his parents' home. After numerous resuscitation attempts, he was stabilised with an ACS for several years. When the French law was voted in April 2005, his parents requested its application for their son, in order to put an end to his artificial life. Facing the geriatrics department's physicians opposition (the patient having been placed there for lack of adequate lodging adapted to his situation), the parents then contacted Jean Leonetti (the deputy who initiated this law). In the end, the doctors begrudgingly accepted to take Hervé Pierra off AHN. The conditions surrounding this “passing away” were a painful experience for Mr and Mrs Pierra. Their anger involving what they considered to be an unacceptable termination of life received intense media coverage (for example: Headliner story for the 8 pm news bulletin, on national channel). A book [7] relates their experience during those agonizing days. These tragic events turned them into pro-militants for the legalisation of lethal injections, via the ADMD association (French “Right to Die with Dignity” association). In regular media appearances, they justify their pro-legalisation stance by the suffering they say this ordeal caused them, and their son, to endure.

In 2004, dentist surgeon and sports enthusiast Patrick Koffel had a motorcycle accident that plunged him into an ACS. He was kept alive by AHN, which his wife and family requested be stopped several years later. Via their mutual lawyer, they entered in contact with the Pierra family and went on to mobilize various national figures, such as Jean Leonetti and Régis Aubry (as President of the National Monitoring Committee of the development program for palliative care). Following their insistent interventions, the doctors at the centre where Patrick Koffel was being kept reluctantly gave their consent to terminate his AHN. The patient died several days later, in what his loved ones deemed as “unacceptable conditions”. A new media campaign was then launched “to expose the inadequacy of French law” in relations to this tragic situation. This media campaign also demanded the legalisation of lethal injections. A full-page article entitled “A Father's Death Revives Leonetti Law Limits' Debate” was featured in the March 13th 2009 issue of the daily newspaper “Le Monde”.

In both cases, the families were shocked by (what they perceived to be) the doctors' attitudes and the fact that deep continuous sedation was not given to the patient during the withdrawal of AHN.

These two items seem to have played a major role in the origin of the conflicts surrounding these situations. Both families describe an almighty, arrogant medical conduct that issued guilt-inducing, judgmental views on their values. They evoke not having been listened to enough, in regards to the intense emotional distress they went through during that time period. They also mention certain manifestations on the patient's part, which they interpreted as being signs of pain or discomfort. At the insistence that they be relieved, doctors opposed the fear of risking to hasten death. These responses appeared to the families as being inhumane, as well as irrelevant, due to the context. In their testimonies, given several years later, it seems that if the families

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