

## Editorial

### *The Diving Bell and the Butterfly*

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Received 8 May 2009; accepted 10 May 2009

I have re-seen (and re-listened to) *The Diving Bell and the Butterfly* (2007) by Julian Schnabel, this time accompanied by the article of Dr. Eduardo Clavé<sup>1</sup>, an internist at the Hospital Donostia and a colleague at the Health Care Ethics Committee, of which he has been president for many years.

Previously, medical and bioethical journals have published a few articles or notes about this film, acclaiming it as a work of art owing to its candid description of human nature -how we fall into the slough of pain and suffering, but also how we re-emerge when we receive the smallest bit of attention and love<sup>2</sup>; and confirming that it is indeed a classic in many programs aimed at the medical humanities across the world<sup>3</sup>. However, in that article as far as I am aware Clavé is the first to offer an extended commentary of the film, and my first reaction is one of thanks to him for having decided to write one, knowing as I do that his work load leaves him little time to engage in such activities. Naturally, this is no excuse, because in this film we are witnesses to a miracle, and not in Lourdes. I mean the miracle of seeing and hearing how a patient with *locked-in syndrome*, Jean-Dominique Bauby, is able to write that book, letter by letter, with the sole aid of his left eyelid, his memory and his imagination.

Well familiar with the self-critical and at the same time very amenable spirit of Dr. Clavé, I was not surprised to learn that he has found the conduct of some of the health staff depicted in the film to belong

to a state of “emotional illiteracy”. Neither was I surprised by his valuable reflections about the interior and exterior resources that even a patient such as Jean-Do has to get on with life, at least as far as his illness will permit. It does not seem casual that many of the patients treated by Dr. Clavé have respiratory problems similar to those that eventually kill the main character of the film. Although there are never two cases identical to each other, and that of Jean-Do is not usual, owing to the characteristics of the unit where he works (Mid-Stay Unit at a tertiary hospital), Clavé attends to patients undergoing very dramatic situations that, despite different variables and nuances, resemble those of Jean-Do. This familiarity with the situation leads the focus of the film to acquire emotion and to emanate empathy towards the patient.

*The Diving Bell and the Butterfly* is a medical film, as we see from the credits with their collage of X-ray plates, but its interest transcends the clinical setting. It is also a fable about father-son relations and the communication difficulties of Jean-Do: bridging distances, as a metaphor of the problems of all patients. As stated by Dr. Michael Stein, in his essay *The Lonely Patient*, sick people undergo their illness as a complex of four components: betrayal, fear, loneliness and loss. Betrayed by their own bodies, terrorized patients lose the narrative thread of their lives and face isolation and loneliness; the most arduous task of the health carer is to help them to reconstruct or reinvent their own stories<sup>4</sup>. This is also the huge task of the health professionals featured in the film.

Clavé's article provides all the clinical information necessary to make an ethical judgement of the case of Jean-Do, but -perhaps aware of the fact that cinema is not merely a medium, innocent or neutral- it also offers some considerations as regards how the director, Julian Schnabel, manages to tell a story such as this one. The challenge of filming a patient paralyzed in his room had already been tackled by Alejandro Amenábar in *The Sea Inside/ Mar Adentro* (2004) with notable success, but Schnabel goes beyond this, with a sagacious use of the camera to offer us a subjective, internal and external, view of the patient Jean-Do, a perspective of the patient himself, in scenes that transmit his angst but also his courage, symbolized in the beautiful images of the birth of a butterfly (at min 39 of the film).

There are no cinema makers who can directly transmit the taste of an oyster, but Schnabel has considerable talent in providing images that indeed capture moments of beauty, as impressive as a glacier calving or as fleeting as the wind-driven hair of Josphine (María Hands) as she drives her open-hood car through the mountains on the way to Lourdes (68'). However, it should be noted that he takes poetic licence in the film, not with the book, which is scrupulously followed, but with the biography of Jean-Do.

When the film was nominated for four Oscars in 2008, a magazine revealed certain discrepancies between the script and the true history of Jean Dominique Bauby<sup>5</sup>. Some of the details are minor, such as that he had two children instead of the three that appear in the film (in the *casting* process, the producers were unable to decide which actor to remove, so they stayed with all of them). However, there is a crucial difference as regards the women in his life. In

the film, the mother of his children visits him in the hospital, even though it is agonizingly clear that he is awaiting a visit from his lover, who never arrives. In real life, it was precisely his lover who stayed to the end with him and it was the mother of his children (his *ex-*) who lived apart from him. When Jean-Do died, and his inheritance (including the authors' rights to *The Diving Bell and the Butterfly*) passed to his offspring, for whom she was the legal representative, the ex-wife assumed control of the transition from the book to the film, demanding the pertinent changes in the script with a view to appearing in a more favourable light.

It may seem trivial, but the fact that one way or another "we all need recognition" (56') is yet another great truth reflected in this excellent film. My own acknowledgements certainly go to Eduardo Clavé.

### Acknowledgements

The Editors would like to thank the translation team of the Languages Service of the University of Salamanca for their collaboration in the English version of this Journal.

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