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The struggle for autonomy [La lucha por la autonomía]

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NOTAS BREVES

THE STRUGGLE FOR AUTONOMY: TOO MUCH, TOO LITTLE OR NOT AT ALL?

LA LUCHA POR LA AUTONOMÍA: ¿DEMASIADO, POCO O NADA?

Zohar Lederman* and Michelle Piperberg**

Palabras clave: bioética, autonomía, toma de decisiones, relación médico-paciente.

Key Words: bioethics, autonomy, decision-making, patient- physician relationship.

In Connecticut (U.S), a 86-year-old male lies in his hospital bed, gasping for air, holding his head in a typical Socratic position, contemplating god knows what, not saying a word. His family is there too: his son, daughter in law and a close neighbor. The son is quiet, while the two women are trying to convince the patient to allow us to treat his right pneumothorax. The patient is tired. He is pale and sweating, and he is not getting enough oxygen. We want to treat him by simply sticking a small needle into his chest to free the trapped air and make a world of difference. But we can't because the patient doesn't want us to, and he

has a Do Not Resuscitate order, so we do nothing. Apparently, someone botched his knee surgery a couple of years back, and he has been suffering from it ever since. He doesn't want any more pain, he doesn't want to be touched or/and poked by physicians anymore, but just to be left alone, and perhaps to die peacefully.

In Florida (U.S), a 92 year-old woman with Alzheimer's is brought to the hospital with an unusually sallow complexion. This is her first time in a hospital since giving birth some 60 years earlier. The young physician in the internal department approaches her daughter and with no reservation utters,

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while looking at the chart, «Do you want her to be resuscitated?» The daughter, dumbfounded, mumbles something that sounds like «no» and the physician scribbles it down onto the chart. There is no discussion, no explanation of the implications of her choice. He may never ask her again, and the next physician coming the following day might assume that what the chart says goes, as long as it fits with their judgment in the relevant moment, of course.

In Israel, a 31 year-old male with depression has been hospitalized for the last 3 months in a psychiatric department. After not having responded to any of the prior treatments, he is prescribed Lithium, which might have serious adverse effects. If ineffective, the next step would be electroconvulsive therapy (ECT). Two weeks earlier, the psychiatric staff had promised the family that they would begin ECT but changed their mind. Disturbed by this patient's suffering, his younger brother urges the medical staff to begin ECT immediately. The medical director responds swiftly- «there are limits! Only we determine how to treat our patients!»

In 1973, when the American Hospital Association adopted a Patient's Bill of Rights¹, a new paradigm of patient-physician relationship was being developed. The bill underscored the right of individuals to participate in treatment decisions by giving consent or refusing treatment, and also the right to

be properly informed of the diagnosis and prognosis. The new paradigm stressed that the main guiding principle should be «respect for autonomy», so replacing the older paradigm that emphasized the principle of paternalistic beneficence.

However, this model of autonomy is often interpreted as the physician's role being simply to provide the relevant information while leaving the decision-making completely in the hands of the patient or his/her family. As described by Pauline Chen:

The patient was dying, and the young doctor had organized a meeting with the family to talk about withdrawing life-support machines and medications and starting comfort measures. The family had spent the entire meeting asking questions but then refused to make any decisions or withdraw any treatments. The doctor said disappointed: *«I spent all this time telling them we could continue to inflict pain on their loved one or we could make him comfortable... I told them suffering or comfort - it was their decision. But in the end, they made no decision and just walked right out of the room.»*²

This description, together with the three cases we have described above, may suggest that the autonomy model might be inappropriate in some situations,

1 Available at http://www.patienttalk.info/AHA-Patient_Bill_of_Rights.htm

2 Chen, P. W., «Letting Doctors Make the Tough Decisions». *The New York Times*. August 11, 2011. (Our italics).

and overplayed to mere absurdity in others³. Perhaps, it is not the case that one's responsibility ends when another's begins, or vice versa.

By criticizing the autonomy model we do not hope to support the paternalistic paradigm, given its lack of attention to the enormous moral, religious and cultural diversity in our western society. Rather, we suggest that there is room to place our trust in a patient-physician relationship where decisions are accepted by all parties with the patient's interests first, the family's will and needs, the physician's knowledge and the resources of the society.^{4,5,6} As Garasic writes: «once the role of autonomy as the leading

principle in bioethics is understood [...] we will be able to embrace a new vision of autonomy that will help us to deal with relatively similar cases in the most appropriate manner without resorting to a patently biased interpretation of this notion.»⁷

To paraphrase Aristotle, we should adopt the «middle ground» between what could be called strong paternalism and an autonomy model falsely understood as atomism, and in any event, we should always emphasize that »respect for the patient's dignity, rights and values should guide all patient-physician-caregiver interactions.»⁸

3 For an example of an underplayed autonomy, see Walker, W. M., «Review- Do Relatives have a Right to Witness Resuscitation». *Journal of Critical Nursing* 1999, 8, 625-630.

4 Daniel P. Sulmasy, L. S., «Substituted Interests and Best Judgment- An Integrated Model of Surrogate Decision Making». *JAMA*. 2010, 304, (17), 1946-1947.

5 Callahan, D., «End-of-Life Care: A Philosophical or Management Problem». *The Journal of Law, Medicine and Ethics* 2011, 39 (39), 117.

6 Timmermans, S., *Sudden Death and the Myth of CPR*. 1 ed.; Temple University Press: Philadelphia, 1999. After comparing the price for the hospital cessation of a CPR that was initiated in pre-hospital settings (50\$) versus the continuation of it (2000\$), Timmermans suggests that we should be more cost effective in this regard and not perform futile CPRs.

7 Garasic, M. D., *Freedom, Consent and Autonomy in Bioethics: Justifications for Enforced Medical Treatment and its Refusal*, PhD Thesis, LUISS University, 2011, p.104

8 Mitnick S, Leffler, C, and Hood VL, for the American College of Physicians Ethics and Human Rights Committee. Family caregivers, patients and physicians: ethical guidance to optimize relationships. *J Gen Intern Med*. 2010; DOI 10.1007/s11606-009-1206-3. Available on SpringerLink at: <http://www.springerlink.com/openurl.asp?genre=article&id=doi:10.1007/s11606-009-1206-3>.

