



Original article

Through the bioethical retrospectroscope

A través del retrospectoscopio bioético

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Received 24 February 2015; accepted 2 March 2015

Abstract

A retrospectroscope is understood here as a fictional instrument through which the past history of certain ideas can help the understanding of their present sense, including the awareness of how our ideas may have drifted off the path. Concretely, this retrospectroscope will seek out the origins of the ethical principles that are so prominent in contemporary bioethics and show how interpretations of these principles have led contemporary bioethics astray, making paradoxes and dilemmas out of what should be resolutions and illuminations. This essay explores, in particular, how the principle of autonomy originated in the protection of subjects of biomedical research and then moved into the relationship between physicians and patients. This shift took place without sufficient recognition of the significant differences between these settings. Respect for autonomy clearly has priority as an ethical principle in the endeavor of medical research. It may not have such priority, at least not in the same sense, in medical practice. The Belmont Report (which concerned medical research) defined Respect for Persons as “the ethical conviction that individuals should be treated as autonomous agents...”, and stated that this autonomy was self-determination. Clinical medicine, however, differs from research radically. It begins with a person bringing an apparently compelling need to a practitioner. Healing is a helping activity, focused on response to a specific request from a specific person in need. The primary moral quality of this activity is the formation of a trusting alliance between physician and patient, in which the focus on the patient’s needs is straight and clear, communication is honest and illuminating, and acceptance and collaboration are real. At the same time, the therapeutic relationship must often be formed at a time when the autonomy of the patient is often buried deeply under pain, debility, and physical and moral distress, or extinguished by radically altered mental status. If one wishes to express that alliance in moral terms, one might still

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invoke the same phrase, Respect for Persons. But that phrase should take on a quite different meaning in the therapeutic alliance than it has in the research enterprise. Unfortunately, in most of the current literature the issue of Respect is focused almost entirely on Informed Consent, the procedure in which autonomy is supposed to be realized.

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Keywords: Autonomy; Respect for person; Informed consent; Therapeutic alliance

Resumen

En este documento, se entiende por retroscopio un instrumento ficticio a través del cual, la historia de ciertas ideas puede ayudar a comprender su sentido presente, lo cual contempla también la conciencia sobre cómo nuestras ideas pueden haber cambiado de rumbo. En concreto, este retroscopio buscará los orígenes de los principios éticos que son tan predominantes en la bioética contemporánea y muestra cómo las interpretaciones de tales principios han desviado del camino a la bioética contemporánea, para formar paradojas y dilemas en lugar de hallar soluciones y esclarecimiento. En particular, este ensayo explora cómo el principio de la autonomía dio origen a la protección de los sujetos en el contexto de la investigación biomédica y se trasladó a la relación entre médicos y pacientes. Este cambio tuvo lugar sin un reconocimiento suficiente de las diferencias significativas entre ambos entornos. El respeto a la autonomía claramente tiene prioridad como principio ético en el marco de las investigaciones médicas; pero quizá no tenga la misma prioridad, o al menos, no en el mismo sentido, en el entorno de la práctica médica. El Informe Belmont (enfocado en la investigación médica) definió el respeto a las personas como “la convicción ética de que los individuos deben ser tratados como agentes autónomos...”, y declaró que esta autonomía se presenta en forma de autodeterminación. Sin embargo, la medicina clínica difiere radicalmente de la investigación. Comienza cuando una persona se presenta aparentemente con una necesidad imperiosa ante un profesional de la salud. La curación es una actividad de ayuda, enfocada en dar respuesta a una necesidad particular de una persona particular. La calidad moral primaria de esta actividad es la formación de una alianza de confianza entre el médico y el paciente, en donde el enfoque en la necesidad del paciente es claro y directo, la comunicación es honesta e informativa y la aceptación y colaboración son reales. Al mismo tiempo, la relación terapéutica con frecuencia debe forjarse en el momento en que la autonomía del paciente queda profundamente sepultada bajo el dolor, la debilidad y la angustia física y moral, o incluso extinta debido a un estado mental radicalmente alterado. Si se deseara expresar esta alianza en términos morales, se podría utilizar la misma frase: respeto a las personas. Pero, en la alianza terapéutica, estas 3 palabras deberían adquirir un significado muy distinto que el que actualmente se le da en el campo de la investigación. Desafortunadamente, en la mayoría de la literatura actual, el tema del respeto se centra casi por completo en el consentimiento informado, el procedimiento por el cual, supuestamente se preserva la autonomía.

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Palabras clave: Autonomía; Respeto a la persona; Consentimiento informado; Alianza terapéutica

A retrospectoscope is a fictional instrument that looks into the past. Unlike clinical scopes that view a present pathology in detail, retrospectoscopes look into the past as it is evolving into the present. Like the Hubble telescope, what it sees on Saturday March 5, 2011 is a present light that originated thousands of light years before today. This fictional retrospectoscope was invented by Dr. Julius Comroe, founder of the Cardiovascular Research Institute at UCSF. In his book *Retrospectoscope* he traced the path from basic science to clinical application of many discoveries, including some that went wrong. Dr. Comroe's book was published in 1977, four years after I began to teach medical ethics at UCSF. He gave me a copy and I think I learned its lessons. I now employ his marvelous fictional instrument to peer into the past of bioethics, not merely out of curiosity but to discern how our ideas may have drifted off the path.

This retrospectoscopic look into the history of bioethics could focus on many different views. It could examine the way in which medical technology raised ethical questions, a topic that I explored in my book, *The Birth of Bioethics*, or study the cultural settings in which certain forms of medical ethics arise, as I did in my *Short History of Medical Ethics*. In this essay, my retrospectoscope will seek out the origins of the ethical principles that are so prominent in contemporary bioethics. I will note not only their evolution, but also discover certain ways in which interpretations of these principles have led contemporary bioethics astray, making paradoxes and dilemmas out of what should be resolutions and illuminations.

In the earliest days of bioethics, a trio of ethical principles emerged as guides to decision-making: respect for persons, beneficence/non-maleficence, and justice. These principles became popular foundations for teaching bioethics and common references to guide ethics committees and consultations about clinical cases. Ethical principles, however, are deceptive. Their names remain the same over centuries, giving the impression that they refer to unchanging guides to action. Yet, the problems that gave rise to these principles shift as new social, cultural, and scientific ones surround them. The understanding of the meaning of the principles themselves deepens with time and, indeed, conceptual and logical mistakes can be slowly recognized.

This essay explores how the principle of autonomy originated in the protection of subjects of biomedical research and moved into the relationship between physicians and patients. This shift took place without sufficient recognition of the significant differences between these settings. Similarly, the principle of beneficence, drawn from the Hippocratic ethical tradition, has moved into an era of therapeutic pluralism,

in which so many options for treatment are available that the line between providing a benefit to a patient and doing harm become blurred. The principle of justice, also originating in the debate over research with human subjects, has migrated into the politics and policies of health care.

Those who work on the ground of clinical bioethics, rather than in its academic towers, might not recognize these significant changes (indeed, the academicians themselves often do not). The practical tasks of deciding about the ethical propriety of a form of treatment require both clear perspective of the circumstances and a correct understanding of the principles that should guide action. It is this correct understanding that needs constant refocusing. The retrospectroscope can reveal how to refocus, as the past evolves into the present.

Those of us who contributed to the earliest bioethical speculation and writing were full of insights but short on method; we wandered like the ancient Greek philosophers proclaiming our insights but without a pattern of ideas to pull them into an order that could be taught and applied to scientific advances and clinical problems. That method suddenly appeared in 1979. In that year *the Belmont Report of the National Commission for Protection of Human Subjects of Biomedical and Behavioral Research* and the book *Principles of Biomedical Ethics* by Tom Beauchamp and James Childress both appeared in print.¹

Both of these works were woven around a structure of principles, three of them in the case of *Belmont* and four in the case of *Principles*. The principles had (almost) the same names: Respect for Persons—called Respect for Autonomy in *Principles*—Beneficence and Non-Maleficence (linked together in *Belmont*) and Justice. The story of how these two works developed, converged, and differed has been told in many ways; I have told my story in the *Birth of Bioethics*, from my standpoint as a member of the National Commission.² I do not intend to rehearse that story today but rather to suggest how the presence of a single template, made up of common words and used as the ethical foundations of both research ethics and of clinical ethics, has caused confusion and misconceptions.

Here is where the confusion begins. Respect for autonomy clearly has priority as an ethical principle in the endeavor of medical research. It may not have such priority, at least not in the same sense, in medical practice. Let me explain. The Commissioners

¹ The Belmont Report (1979), Beauchamp and Childress (1979).

² Jonsen (1998, 2000).

of the National Commission came to see that the practices called research, and indeed, the entire institutional structure of biomedical research, was radically different from medicine as a clinical encounter. The opening paragraphs of *The Belmont Report* outline those differences, which had been obscured during a century of growth in scientific research. The most important difference, now so commonly recognized as to seem trite in the uttering, is that medical practice seeks the cure and health of an actual patient, while research intervenes in the life and body of a person, not to benefit them, but to search for benefits for future patients and populations.

The template of principles invoked in the *Belmont Report* is intended to give moral structure to the entire enterprise of research. It must be seen, as a whole, as the free and voluntary offering of self to a risky activity aimed at a social good, the advancement of science and the improvement of medicine. *Belmont's* principles are not intended to represent the motivation of researchers or of participants; they are not an exhortation. They aim primarily at the ways in which research protocols and practices should be designed and implemented. In this setting, the demands of the principle of respect for autonomy dominate the design. The free, willing, comprehending engagement of the subject is unquestioningly the foundation of the ethics of this social endeavor. Under no circumstance is a human being to be reduced to the status of a means to another's ends.

Belmont defined Respect for Persons as “the ethical conviction that individuals should be treated as autonomous agents...” The *Report* then stated that this autonomy was self-determination, or the “capacity of deliberating about personal goals and acting under the direction of such deliberation”; respect for autonomy is “refraining from obstructing the actions (of autonomous persons) unless they are clearly detrimental to others.” *Belmont* made quick jumps through the massive literature of moral philosophy, linking the vastly different ideas of Immanuel Kant and John Stuart Mill. These quick leaps propel the principle of Respect for Persons into a moral barrier against trespass on a person's body, mind, or life. It fundamentally says, “stay out of my life unless I explicitly and deliberately invite you in.”

Clinical medicine differs from research radically. It begins with a person bringing an apparently compelling need to a practitioner. Healing is a helping activity, focused on response to a specific request from a specific person in need. The primary moral quality of this activity is the formation of a trusting alliance between physician and patient, in which the focus on the patient's needs is straight and clear, communication is honest and illuminating, and acceptance and collaboration are real. At the same time, the therapeutic relationship must often be formed at a time

when the autonomy of the patient is often buried deeply under pain, debility, and physical and moral distress, or extinguished by radically altered mental status.

In the formative years of bioethics, the clinical relationship was suffering from a conceptual malaise. Medical sociologists asserted that physicians exercised untoward dominance towards their patients. They assumed authority to make unilateral decisions for their patients.³ At this time, the culture as a whole had turned strongly anti-authoritarian. The term “paternalism” began to characterize the relationship between doctors and patients. In this setting, the relationship was defined as an antagonistic one.

Application of respect for autonomy in the field of research ethics is very appropriate. The researcher seeks entry into the personal space of the subject, intending, as it were, a sort of trespass. Consent provides permission to pass. In the clinical setting, the patient seeks help and the physician offers it, starting a process in which an alliance of interests and exchanges must be forged. It is not, in its beginnings or in its process, an antagonistic one. Certainly, its ethics should not open with the supposition of enmity, as do the ethics of just war.

If one wishes to express that alliance in moral terms, one might still invoke the same phrase, Respect for Persons. But that phrase should take on a quite different meaning in the therapeutic alliance than it has in the research enterprise. It must reflect a respect, not so much for the choices of individuals and the protection of their moral and physical space, as a respect for their dignity as persons who claim a unique place in the world of medicine: as those who need help in a world that is self-proclaimed as a helping enterprise.

When Beauchamp and Childress translated the Belmont Principle of Respect for Persons into their book as Respect for Autonomy, they wrote, “autonomy is a form of personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself.”⁴ Their chapter on Respect was focused almost entirely on Informed Consent, the procedure in which autonomy was realized.

Other early bioethicists, even Jonsen, Siegler, and Winslade in their otherwise excellent *Clinical Ethics* of 1982, took the same route. We also defined respect in

³ Freidson (1970).

⁴ Beauchamp and Childress (1979), p. 56.

the limited terms of the *Belmont Report*, terms more suited to the problem of research ethics, namely, the prohibition of alien procedures, than to clinical ethics, the establishment of a therapeutic alliance. We focused as well on informed consent. All these early bioethicists failed to recognize significant differences in the meaning of Respect for Persons, and because they, consequently, did not revise the research meaning of that principle then they moved it into clinical ethics. We opened the way to many strange questions: can a patient demand *anything* from a physician? When a patient rejects a medical recommendation, must the doctor walk away? What can we do if consent cannot be obtained, particularly when surrogates disagree or when the patient is without surrogates? In addition, we opened the door to the relationship as a commercial one, in which the patient shops for desirable therapies and opinions. The sad result is that the relationship remains an adversarial one, now not because of paternalism but because of the dysfunctional structures of medical care and health care financing.

The second foundational principles of the early bioethics constitute a set: non-maleficence and beneficence. These are combined in Belmont into a single principle, and divided into two conceptually distinct ones in Beauchamp and Childress. They seem rooted in the most ancient ethics of the healing arts, the Hippocratic injunction, "Be of benefit and do no harm." However, the retroscope shows how those ancient words become distorted through time and space.

The benefit of ancient literature referred to a repair of a broken structure or the extinction of pain. Another Hippocratic injunction states that the goals of treatment are threefold: to relieve suffering, to lessen the violence of disease, and to refrain from attempting to cure those who are overwhelmed by their disease." The first two goals aim at a tangible benefit, experienced by the patient; the third, though negatively stated, is also experienced by the patient: it tells physicians not to add the burdens of treatment to the burdens of an incurable disease.

In traditional medicine, these principles came to mean that no medical intervention should entail a risk that is not justified by the intended benefit, relief of pain, or reduction of the violence of disease. In the Belmont Report, these principles reveal that the research enterprise does not proffer therapeutic benefits to present subjects but aims toward improvement of future interventions. Thus, any risk entailed by the research intervention must be explicitly accepted by the research subject.

So, what do we see through this bioethical retroscope? The light coming from the past shows us present realities, not as they are but as they were. The bioethi-

cists who were peering through that instrument thought they had seen concepts that could describe the world of medical practice sufficiently to build an ethics around it. We now realize that the description has been subtly overtaken by time and innovation. The world of medical practice must be seen in a new light, and the ethical concepts must be illuminated by clearer and sharper beams of understanding.

References

- Beauchamp, T.L., and Childress, J.F. (1979). *Principles of Biomedical Ethics*. New York: Oxford University Press.
- Freidson, E. (1970). *Professional Dominance: The social Structure of Medical Care*. New York: Atherton Press.
- Jonsen, A.R. (1998). *The Birth of Bioethics*. New York: Oxford University Press.
- Jonsen, A.R. (2000). *A Short History of Medical Ethics*. New York: Oxford University Press.
- The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1979). Washington DC: Government Printing Office.