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BIOETHICS IN ACADEMIC ROOMS: HEARING OTHER VOICES, LIVING IN OTHER ROOMS

For bioethics, the twentieth century was the century of autonomy. In the wake of atrocities committed on individuals in the name of science – the Nazi experiments, Tuskegee, Willowbrook, the Jewish Chronic Disease Hospital, and the abuses brought to light by Beecher and Pappworth – an emphasis on autonomy was fitting. But as bioethics began to move beyond national borders in the late twentieth and early twenty-first century, use of the concept of autonomy has become increasingly problematic. Autonomy seemed to work well in the academic rooms of Western, individualistic societies, but when research was exported to societies outside of the West, it became clear that autonomy, and the principlist algorithm of which it was a part, failed to capture non-Western conceptions of ethical obligations. In these societies, decisions about one's body and one's welfare are not appropriately taken by solely by the individual in question; rather, these decisions are made in consort with others, or by others. The challenge to autonomy generated outside of the West has since come back to the West, generating questions about the usefulness of the concept even in individualistic societies. When we listen to other voices and live in other rooms, our academic perspectives are forced to change.

But we are all subject to culture shock. Confronted with another way of thinking about ethical obligations, defenders of autonomy and the principlist framework have gone to great lengths to defend their ideas, introducing tortured notions such as "second-order autonomy" in an effort demonstrate that all peoples everywhere share the Western idea of individual autonomy. But, in fact, these other voices in different rooms are making it apparent that autonomy is dead.

Using data from research on bioethics in societies outside the West and from studies of the problems with the (mis)use of autonomy in the West, I chronicle the demise of the value of the concept. Evidence from non-Western societies shows how principlism is either ignored or modified in order to accommodate the way ethical obligations work in these societies. Evidence from the West shows the way paternalism "infects" autonomy: in some cases autonomy is used to flee from professional responsibility and abandon patients (it is your decision!), in other cases the choices given

to patients are artificial, constrained by the bias of the information given.

The demise of autonomy does not mean a return to the bad old days of paternalism. On the contrary, the cold concept of autonomy is gradually being replaced by the richer concepts of respect and obligation. These concepts recognize the power differential between doctor/patient and researcher/subject and offer a way to realize the obligations inherent in each role.

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THE VOICE OF BIOETHICS IN THE ARTS

In 1962, Watson, Crick and Wilkins were awarded the Nobel Prize for the discovery of the structure of DNA. But 1962 was also the year of the premiere of Edward Albee's classic play *Who's afraid of Virginia Woolf*, devoted to academic campus life, childlessness and alcohol abuse. This play contains rather interesting discussions on science, such as the following, between Nick (a biologist) and George (a historian):

George: Martha says you're in the Math Department, or something.

Nick: No...I'm not... I'm a biologist. I'm in the Biology Department.

George: (After a pause) Oh. (Then, as if remembering something) OH! You're the one! You're the one's going to make all that trouble... making everyone the same, rearranging the chromozones, or whatever it is. Isn't that right?

Nick: (With that small smile) Not exactly: chromosomes.

George: ... I'm really very mistrustful. Biology, hunh? I read somewhere that science fiction is really not fiction at all... that you people are rearranging my genes, so that everyone will be like everyone else. Now, I won't have that! ... There will be a certain...loss of liberty, I imagine, as a result of this experiment...but diversity will no longer be the goal. Culture and races will eventually vanish...the ants will take over the world.

Nick: You...you don't know much about science, do you?

In my view, authors such as Albee may be regarded as seismographs of cultural developments and social

concerns, a kind of physician whose job it is to assess the mood and physical condition of their own time. Apparently, this gifted author had sensed that, in the 1950s and 1960s, chromosomes were in the air, although public culture still had to attain some level of fluency with regard to the new bio-speak that was emerging.

Genres of the imagination, such as plays, may function as test-beds, exploring future scenarios and probing options and concerns. In the 1960s, chromosomes were offering a kind of window into the intimate essence of life itself. How would this new knowledge be used and abused? In 1935, Husserl had talked and written about the “crisis” of science. He had argued that normative issues pertaining to the cultural and social meaning of new technologies, had been removed from the domain of objective science as such, and were now regarded as merely “subjective” or “emotional”. Apparently, we were no longer able to address the normative dimensions of techno scientific development in a rigorous way.

And this open deliberative space entailed an invitation, to bioethicists on the one hand and to artists such as novelists on the other. Since then, as a flanking discourse to science on the one hand and bioethics on the other, the genres of the imagination have been playing an important role.

Yet, in the early 1960s, ideas about the societal impact of the new life sciences were still fairly utopian (or dystopian) and futuristic. Since then, we have witnessed the emergence of a scientific revolution: an unprecedented era of knowledge production in the life sciences on a massive scale. Indeed, to quote a phrase from Friedrich Engels, ideas concerning genetic manipulation, genetic screening and artificial reproduction have moved from mere ‘utopia’ to real ‘science’. After the double helix (1953) came the Human Genome Project (HGP, 1990-2003) and now, we are entering the era of the personal genome. In his book *The Language of Life* (2010), Francis Collins, former Director of the HGP and now Director of NIH, describes what this new revolution has in stall for us as follows: “Healthy individuals are increasingly able to discover some of their body’s inner secrets and take appropriate action. The potential for individual prediction is beginning to spill out to the general public, offering the opportunity to take more control of your fate”. In other words, the personal genome will make us the managers of our own health condition, with our personal DNA as starting capital as it were.

Again, genres of the imagination may play a role in probing and testing claims such as these. For instance, shortly before his death, Michael Crichton (author of *Jurassic Park*, the most famous genomics novel so far) published his novel *Next* (2006). The title refers to Next Generation Sequencing, the new high through-put sequencing technologies that will make the

personal genome era possible and the personal genome affordable for all. In his novel, Crichton explores what will happen when individuals start thinking about themselves, start assessing themselves and others, in terms of the genes that can be detected on their genomes, such as the thrill-seeking gene, the sociability gene or the infidelity gene, and so on. Much like Albee’s play can be regarded as a flanking document to the work of Watson and Crick, the books by Collins and Crichton can be regarded as complementary, as flanking documents: mirroring and questioning, supporting and / or criticising, challenging and rebuking one another.



And not only novels and drama may play this role. Bio-art or even music may function in similar ways. DNA music has become something a hype. The biologists and musicians involved in this claim that, in order to really understand and appreciate our genome or our DNA, we have to make it audible, we have to listen to it, we have to translate it into a music score, which is not all that difficult, because there are many similarities between music and life, between a genome sequence and a music score (see for instance Noble 2006). And last year, a statue was unveiled on the lawn right behind our Faculty of Science. It is a statue of a human being: a large pile of cloth on which is printed (in very small type) the billions of letters composing the DNA of a Dutch clinical geneticist called Marjolein Kriek, the first woman whose personal DNA was sequenced and published. This statue raises a whole series of issues and questions concerning the meaning and significance of sequencing technologies for our understanding of human life and human identity. By merging and forging these various genres and sources into one “total work of art and science”, our understanding of the meaning of genomics for human life and health can be deepened and enhanced.

References

- Francis S. Collins (2011) *The Language of Life. DNA and the revolution in personalized medicine.* New York etc.: Harper.
 Michael Crichton (2006) *Next.* New York: Harper Collins.