

EACME Newsletter

European Association of Centres of Medical Ethics

Executive Office: Angelique Heijnen
Maastricht University, Dept. Health, Ethics and Society
Faculty of Health Medicine and Life Sciences
P.O. Box 616
6200 MD MAASTRICHT, THE NETHERLANDS
Tel: +31 43 3882145
Fax: +31 43 3884171
A.Heijnen@maastrichtuniversity.nl
www.eacmeweb.com



Number 33 – May 2013

CONTENTS

EDITORIAL R. Porz	1
CROSSING BOUNDARIES CONNECTING CULTURES Learning from a participative social media approach to improve public mental health M. Knibbe	2
RESEARCH BIOBANKING: BIOETHICAL ANALYSIS – A SUMMARY M. Šuleková	3
INTERNATIONAL VISITING FELLOW Institut für Medizinische Ethik und Geschichte der Medizin – Bochum F. D'Abramo	5
INTERNATIONAL VISITING FELLOW Institut für Medizinische Ethik und Geschichte der Medizin – Bochum J. Barutta	5
E-SANTE, LITTERATIE EN SANTE, WEB 2.0 floraison d'initiatives avec des enjeux éthiques J. Martin	6
BOOK REVIEWS	7
NEW ASSOCIATE MEMBER	10
EACME PRIZES	10
DEADLINE NEXT NEWSLETTER	10
ANNOUNCEMENTS	10
EDITORIAL BOARD	11

EDITORIAL

Why (again) did I become an ethicist?

Why am I posing this question? No, not because I am in a midlife crisis and no, I still think my job is fun. But sometimes, and especially lately, I keep asking myself: why again did I become an ethicist? Was it a purely rational decision or did the field of bioethics attract me on an intuitive level? I believe it was a rational choice – I wanted to work at the intersection of medicine, humanities and natural science. But was it really like that? It sounds complicated but I think this was indeed the reason. Was it?

Why do I keep wondering? The reason is the following: I work as a clinical ethicist in a big hospital and I give lessons to a lot of students: medical students, nurses, midwives, physiotherapists – I get in touch with almost all kinds of health care professionals in the course of their education and training. And these young people are increasingly skeptical towards my work: “Mr. Porz, why are you doing this, at all?”, “Do you ease the conscience of the university hospital?”, “Are you a ‘fig leaf’?”, “Do physicians take you seriously?”. Basically, I appreciate my students’ openness, skepticism and honesty. At the same time, though, I am not constantly in the mood for justifying the scope and limits of ethics. However, students’ questions help me to get an idea of what they expect from ethics in healthcare. And (unfortunately) they often expect ethics to make a decision when no one else can, much like an arbitrator. But this is not my understanding of ethics. I believe that ethics should reflect upon things, uncover implicit normativities and think ahead.

My phone is ringing, a journalist is calling. He asks for a quick statement on whether it is ethically justified to send asylum seekers back to their home country. It is urgent, he says, since he wants to publish his online article that evening. With caution and modesty I

explain why I cannot answer such an imprecise question as quickly. "But I thought you're an ethicist!", the journalist counters a little upset and with a hint of reproach. He puts the phone down on me. I start wondering again, why did I become an ethicist again? It is knocking on my door and my younger work colleague enters, Nina Scherrer, a philosopher who is about to begin with her doctoral thesis. Before she can say something, I ask: "Tell me, Nina, why do you want to become an ethicist?" Without much astonishment and firmly convinced she replies: "Ethics is about human action and values – what could be more thrilling?" A short silence ensues. I am smiling. Right, it's as simple as that. How could I forget? Students, journalists, physicians – all of them are entangled in action. I feel reassured.

"So, Rouven, what is in the EACME newsletter?", Nina asks. Of course, the newsletter. I start talking about the text of Mare Knibbe and Mária Suleková who writes about biobanking, and then there are two texts by Joaquín Barutta and Flavio D'Abramo, one book review, event suggestions ... small but mighty, as usual. I hand Nina a copy, hot off the press: Happy reading!

Rouven Porz

Inselspital, University Hospital Bern
General Secretary of EACME

rouven.porz@insel.ch

CROSSING BOUNDARIES CONNECTING CULTURES

Learning from a participative social media approach to improve public mental health

Bianca is a typical entrepreneur from Maastricht, combining businesslike and empathic qualities. She is the owner of a gym and has discovered that people who come to the gym could also be working on their wellbeing in many other ways. Whenever she notices some form of distress she shows her engagement.

As rumor has it, Fabienne, one of her clients, shows excessive shopping behavior. Fabienne has repeatedly forgotten to pick up her son because she was completely absorbed by her shopping. Bianca is worried about Fabienne. One day, when Fabienne is enjoying the sauna at the gym, her quality time is interrupted by Bianca's uninvited caring interference. Bianca starts carefully about paying contribution, however when Fabienne keeps avoiding the problem she confronts her with the gossip. Fabienne looks flabbergasted. Then Bianca tries to show her a new horizon, by telling Fabienne about how she managed to get rid of her

smoking addiction. Now Fabienne explodes, she does not see what smoking has to do with it. And she scolds Bianca for participating in the gossip: 'That is something I do not wish to hear' she shouts, and walks away.

The confrontation between Bianca and Fabienne is a fragment of a short film that is part of 'Bianca in the neighborhood', in short 'Bianca'. Bianca is a mixed media project that has the goal of promoting mental health and resilience in neighborhoods with low incomes and high unemployment rates in the city of Maastricht. It uses a combination of television, radio and social media to reach a broad local public with a series of short, twelve-minute films that offer opportunities to interact about difficult topics in the social and emotional life of neighborhoods; families; professional life and friends. In our research 'Crossing boundaries connecting cultures, learning from a participative social media approach to improve public mental health' we evaluate the making of and the impact of this mixed media project Bianca. I conduct this research together with Klasien Horstman, professor Philosophy of Public Health within the department of Health Ethics and Society (HES) at the University of Maastricht. We also work together with Marten de Vries, emeritus professor in Social Psychiatry, Clemens Hosman emeritus professor in Mental Health Prevention, and the public mental health network that gave birth to Bianca.

The research aims to contribute to the development of new approaches to public mental health, by drawing lessons from the media project Bianca. The project, however, is also of interest to current ethical and policy discussions about citizen and community responsibilities with regard to health. In these discussions a lot is said and written about so-called irresponsible health behavior and communities with low socio economic status (Ises). Conversations between health ethicist or policymakers and citizens in Ises communities about different notions of health, and about responsibilities in public health, are rare. The mixed media project Bianca provides an interesting example of how space can be created for diverse forms of participation in such conversations.

Bianca was developed in a process of 'critical praxis' in which many parties in neighborhood and city life, and diverse fields of expertise of filmmakers; health practitioners; community workers and academics were involved. This critical praxis can be described as collaboratively exploring, analyzing and reflecting on the neighborhood understandings concerning public mental health (see also Walker 1998). This also involves the neighborhood understandings about existing policies and professional activities of health promotion and (public) mental health (see also Horstman and Houtepen 2005; Labonte, Feather et al. 1999; Springgett 2001; Wallerstein and Duran 2006).

The try out film *Fabienne* (fragment above) was an important tool in this process. This try-out film was shown to selected groups of public in so-called narrow castings. In the narrow castings that were held in the participating neighborhoods the film invited many stories and reflections. Participants told about neighborhood relations and reflected on the types of relations in which one could signal and address mental health problems. They explored different ways of providing support and ways of balancing between engaging and respecting privacy. However participants discussed not only their own experiences and positions; during narrow castings people living in the neighborhoods involved in the project, also provided critical discussions of local policies affecting mental health.

In addition to these organized deliberative processes, the making of *Bianca* also contained more playful and spontaneous actions and reactions. The character of Bianca, featuring in the six short films that are central in the project, also interviewed people in the street. In these interviews she invited spontaneous reactions, and stories that became part of the critical praxis of the making of the project. In the making of the project *Bianca* these opportunities for diverse forms of involvement of neighborhoods were important ways for *Bianca* to learn how to become part of local city life. The opportunities for participating in extensive deliberations as well as more spontaneous reactions and associations also helped to include a diversity of voices. Different types of experience and knowledge evoked by the stories exchanged around Bianca were explored. The collaborations were also important to fine-tune the language and styles of Bianca. What kind of language should she use? Whose sense of humor did she share? Who felt offended by Bianca's sense of humor or language?

These processes of collaboration, participation and critical praxis led to some curves, and detours between the initial plans and the final shape of the project. In *Crossing Boundaries*, our research, we map these collaborative trajectories. We use a narrative-ethnographic approach to evaluate the making of *Bianca* as well as its impact and significance for mental health and resilience. The research has also become part of the negotiations about the values and the formal and informal relations that are important to public mental health. At this moment *Bianca* is in the local traditional and social media with six short films, and we are organizing film gatherings and interviewing people in the neighborhoods involved. On the basis of these experiences with *Bianca* we hope to draw lessons for future approaches to public mental health. However *Bianca* may also provide broader lessons about how to create space for citizen and community participation in conversations about public health and the responsibilities it involves.

Mare Knibbe

Maastricht University
Health, Ethics & Society

m.knibbe@maastrichtuniversity.nl

www.biancaindebuurt.nl (in Dutch)

- Horstman, K. and R. Houtepen (2005). *Worstelen met Gezond leven: ethiek in de preventie van hart- en vaatziekten*. Amsterdam, Het Spinhuis.
- Labonte, R., J. Feather, et al. (1999). "A story/dialogue method for health promotion knowledge development and evaluation." *Health Education Research* **14**(1): 39-50.
- Springett, J. (2001). *Appropriate approaches to the evaluation of health promotion*, Routledge, Ltd. **11**: 139-151.
- Walker, M. U. (1998). *Moral Understandings, a Feminist Study in Ethics*. New York, London, Routledge.
- Wallerstein, N. B. and B. Duran (2006). "Using community-based participatory research to address health disparities." *Health Promotion Practice* **7**(3): 312-323.

RESEARCH BIOBANKING : BIOETHICAL ANALYSIS

A SUMMARY

In the last decade, the establishment of organized biobanking has accelerated at both the national and international level. There has been an increase in research projects in genetics and genetic epidemiology that focus on the understanding of the contributions of genes, lifestyle and environment, to the development of complex diseases. New strategies of diagnosis, prevention and therapy for various illnesses are expected to be derived from these studies in the future. Moreover, biobank research is considered by many sources to have the potential to be a key tool in enabling personalized medicine. However, at the same time, new genetic technologies carry significant risks and are thus a cause for concern. There has been vigorous discussion about issues and challenges regarding human tissue research and about the ethical and legal regulation of this field. Activities related to research biobanking also became a topic for bioethical debate. My PhD thesis endeavoured to explore such a debate and attempted to bring both an innovative and critical contribution to this discussion within an Italian context.

The thesis consists of four chapters. The first part serves as a function of the subsequent chapters, describing the scientific reality of biobanking. It deals with the establishment of biobanks, definitions, features, typology and objectives of these tissue and data collections. There are two particularly relevant points here: clarification of the Tower of Babel's terminology concerning biobanks and scientific justification of research based on biobanking. Thus,

identification of the object in examination was the first step to ethical analysis.

The second part presents the *status questionis* related to issues surrounding biobank activities. By examining and drawing from various sources who endorsed the ELSI approach I applied such methodology in my own investigation, laying out the legal, ethical, social, political and economical challenges of research biobanking in both the national (Italian) and international context. From this general examination I then focused on the specific ethical issues (and corresponding ethical-legal as well as ethical-social issues) in this field. This involved topics such as informed consent, privacy, return of results, public trust, risk of discrimination and stigmatization of vulnerable groups, commercialization and benefit sharing. The central concern in pointing out these implications is to solve the problem of how biobanks may be organized and managed such that they follow the realization of the common good as well as guarantee human rights and human dignity.

The third part of my thesis deals with the problem of *informed consent* in biobanking. Biobanks which aim at being long-term research institutions, store samples and data for a multitude of research projects and scientific goals, which has led to complications in obtaining specific consent. The fundamental problem, which has also appeared in expert discourse, is to develop an alternative to specific consent, which until now has been considered as a *gold standard* of biomedical research ethics. Here I analysed various proposals of consent to the collection, storage and use of human tissue samples and data for research purposes. I focused on the different justifications and critiques of *broader* consent proposals and distinguished between ethical and non-ethical argumentation (practical, scientific, economical, sociological). Subsequently, since consent in biobanking is related to the subject's autonomy in making decisions about participation, I examined the different interpretations of autonomy underlying these various consent models, which recalled the theories of autonomy and self-determination by Mill, Kant, Ross and Beauchamp. This investigation into the issue of consent revealed that in ethical reflection on biobanking there is a tension between the 'individual' and 'social' understanding of the subject's autonomy.

Moreover, the bioethical debate revolves around the searching of an appropriate reference theory and guiding ethical principle that is capable of regulating the activities related to biobanking. So, we can find applications of Georgetown's *principlism* and of the principle of respect for the individual's autonomy on one hand and calling for the value of solidarity and altruism on the other. Furthermore, while analysing this debate I also examined two fundamental theoretical approaches in the ethics of biobanking: the protection of human rights perspective and the communitarian

perspective. Whilst one perspective risks being excessively paternalistic and procedural, the other can tend to be rhetoric, purely utilitarian or contractual. Finally, I considered some particular "bridging concepts" aimed at challenging the excessive views and I concluded with a reflection on how autonomy and responsibility is called to act in front of the needs of others, especially people who are (potentially) sick, and on what implications this could have in consent models discussion in biobanking.

The last part of my work is dedicated to the topic of samples control after they are removed from the participants body in the context of biobank research. I treated this question first because it is narrowly connected to the issue of informed consent through which the participants are asked to give special permission regarding the future use of their body samples, and second because it is connected to the specific problem of the donation and commercialization of human tissue. This chapter deals with four important, interconnected themes: the problem of justice and the asymmetry between bio-industry profits and free tissue donations of participants; the ownership of identifiable human tissue; the "multidimensionality" of genetic samples (material, informational, familiar and communitarian) and its connection to the relative topic of biological identity of the subjects involved; the meaning of respect for human dignity in such a context. In the examination of these four themes, the central underlying issue was the difference between the person's relation to his/her integrated body parts and the person's relation to his/her separated identifiable body tissue. I preferred to treat this issue of the "relationship" of the person to it's body samples not in terms of a "belonging to" of property or ownership, but rather in terms of *identity*, whereby the biological identity of the person, family and groups are at stake. Because of this "belonging to", the individual could never be an absolute owner of his/her removed tissue, but at the same time s/he should be considered *in primis* regarding decisions about it.

The ultimate claim of my thesis is that if we allow for the model of *broader* consent, then the participants should have the right to indicate what kind of research they do not want their tissues to be involved with. I subsequently layed out the situations and conditions in which the participant may be in a position to claim this right. In this case, there should be implied the particular instruments for improving the biobank governance (e.g. biobank ethical code) and specific tools for reinforcing of the mantaince of the long-term participant-biobank relationship.

Mária Šuleková

Università Cattolica del Sacro Cuore Rome

maria.sulekova@rm.unicatt.it

Mária Šuleková defended her PhD thesis in public on February 27th, 2013, 9.30hrs, at the *Università Cattolica del Sacro Cuore* in Rome.

Mária Šuleková, Institute of Bioethics, School of Medicine and Surgery, *Università Cattolica del Sacro Cuore*, Rome, Italy

**INTERNATIONAL VISITING FELLOW
INSTITUT FÜR MEDIZINISCHE ETHIK UND
GESCHICHTE DER MEDIZIN - BOCHUM**

International visiting fellow Flavio D'Abramo

A daily interdisciplinary exercise

In February 2011 I presented a paper in applied ethics, at the Institute for Medical Ethics and History of Medicine in Bochum, during the workshop "Human Medical Research: ethical, economical and socio-cultural aspects". In those few days and thanks to experts' presentations, working groups, talks and discussions, it started a fruitful collaboration that is still lasting. Indeed, the presentation I did turned out in a publication edited by Jan Schildmann et al. (Human Medical Research. Ethical, Legal and Socio-Cultural Aspects, Springer Publishers). After that occasion I had the luck to receive a scholarship of 16 months from the Institute. In April 2012 I moved to Bochum, starting commuting in few minutes from the city center, where I live, to the Institute, riding the bicycle or by bus. I felt at home since the beginning. At the Institute, that is located in an old tower, I received a desk, a computer and all the facilities offered by the Ruhr-University Bochum. Two fellows from Argentina and Canada were already at the Institute conferring to the environment an international spirit.

During the first workshop in Bochum the paper I presented was challenged and important contributions for the publication were made by the reviewers. The epistemological and ethical analysis for the use of a particular drug in social and clinical settings were then enriched and deepened. Once arrived in Bochum reviewers became colleagues with whom I started attending research colloquia, seminars and spontaneous talks. At the same time I was able to finish the writing of my Phd thesis that I discussed later, in June, at University of Rome, La Sapienza.

My actual analysis focused on the socio-empirical literature regarding the use of informed consent in genetic and genomic research. This research, which I am doing with Jan Schildmann and Jochen Vollmann,

represents a challenge as it addresses one of the most debated issues of contemporary medical research. Thanks to frequent meetings and discussions with Jan and Jochen and to tips received from other colleagues of the Institute the arguments have been broadened and, at the same time, focused on relevant ethical points. At the Institute for Medical Ethics and History of Medicine I am applying philosophical arguments to the social and cultural aspects of medicine, and vice versa I am informing the philosophical and epistemological analysis on the base of medical and public health practices coming from my colleagues. This interdisciplinary research allows me to have many tools to analyze challenging innovations that contemporary medicine meets. The use of technological instruments and new means for the dissemination of biological information is indeed contributing to the creation of "personalized medicine", a field that is possible to fully appreciate and analyze debating with physicians and social scientists that are present at the Institute. My stay in Bochum is very beneficial as it opens new ways to work with physicists and bioethicists in fields where the analysis of concrete contexts is just the very interdisciplinary daily exercise.

I would like to thank Ruhr-University Bochum and the colleagues of the Institute for Medical Ethics and History of Medicine for their support and friendships.

Flavio D'Abramo

Institut für Medizinische Ethik und Geschichte der Medizin
Ruhr-Universität Bochum

flavio.dabramo@ruhr-uni-bochum.de

**INTERNATIONAL VISITING FELLOW
INSTITUT FÜR MEDIZINISCHE ETHIK UND
GESCHICHTE DER MEDIZIN - BOCHUM**

International visiting fellow Joaquín Barutta

At the beginning of 2011 I met Professor Jochen Vollmann while he was holding a lecture on ethics at the end of life, at the Ministry of Justice and Human Rights, in Buenos Aires, Argentina. By then, I had already completed my medical degree, and was writing my PhD thesis on Epistemology and History of Science. Moreover, I was also working in the field of medical ethics as member of the medical ethics committee at the Italian Hospital of Buenos Aires. However, it was through my exchanges with Professor Vollmann that I decided to dedicate my future efforts to reflect on the moral problems surrounding medicine. With this goal in mind, and supported by an

International Visiting Fellowship provided by the Institute for Medical Ethics and History of Medicine of the Ruhr University, Bochum, in 2012 I travelled to Germany to work on the ethical implications of implementing advance directives in a Latin American setting.

Shortly after my arrival, I presented the main ideas for my research to the rest of the group. Much of my presentation was aimed at providing an account of the Argentinian cultural context and the way it affects medical practice. The comments I received by the members of the group, which were informed by a different cultural setting, in addition of incorporating sound arguments, helped me rethink my ideas from alternative perspectives I did not consider before. This process continued during my whole stay, through our weekly meetings, lunchtime seminars, research colloquiums and daily dialogues with my colleagues, resulting in an increasing clarification of my own intuitions and arguments. An open and rigorous dialogue, also sensitive to our cultural differences, has been, I believe, the necessary basis for such an enriching experience.

I would like to thank all members of the Institute for Medical Ethics and History of Medicine of the Ruhr University for their hospitality as well as their intellectual and financial support.

Joaquín Barutta

Institute for Medical Ethics and History of Medicine,
Ruhr University, Bochum, Germany
Department of Medical Humanities, Italian Hospital
University, Buenos Aires, Argentina

joaquin.barutta@ruhr-uni-bochum.de

E-SANTE, LITTERATIE EN SANTE, WEB 2.0

floraison d'initiatives avec des enjeux éthiques

Mindblowing ... qui bouscule l'esprit comme un ouragan. A l'occasion de ses 125 ans, la Polyclinique médicale universitaire de Lausanne (PMU) organisait en novembre 2012 un symposium sous le titre « Littératie Web 2.0 - Chances et défis ».

La **littératie en santé** est la capacité de trouver de l'information et de comprendre et utiliser ces données de manière à prendre des décisions puis à suivre les instructions thérapeutiques (fondamentalement, il s'agit de lire, écrire, parler, écouter et calculer). Le concept de capacitation des patients (empowerment) en est proche. La recherche a bien démontré les liens

entre le niveau de littératie des patients et les résultats thérapeutiques

De nombreuses études montrent que, y compris dans les pays industrialisés, une proportion notable des malades sont illetrés en matière de santé, ne comprennent pas - ou mal - ce que disent les soignants. Rima Rudd, de Harvard, a eu une formule forte : dans une telle situation, continuer à prodiguer des soins comme si les patients comprenaient est simplement non-éthique ! Le Département de la santé des Etats-Unis a fait développer le « Health Literacy Universal Precautions Toolkit » pour aider les professionnels à être mieux compris des malades*.

L'expression **Web 2.0** a été introduite vers l'an 2000 pour parler de sites qui vont au-delà d'un format statique pour permettre des interactions et collaborations ; donnant lieu à un dialogue par les médias sociaux, avec création de contenus générés par les utilisateurs, au sein d'une communauté virtuelle. Dans ce cadre, le **crowdsourcing** (littéralement, rechercher des compétences dans la foule) est une démarche où on tire profit de la créativité et du savoir faire d'un grand nombre de personnes tout-venant, pour réaliser des tâches qui étaient jusqu'ici effectuées par des experts. Là aussi on voit que peuvent surgir des questionnements éthiques.

Des spécialistes étrangers participaient à ce symposium : en plus de R. Rudd déjà citée, Denise Silber, très active dans ces développements en France notamment, et Beci Mesko, jeune médecin et entrepreneur hongrois, sorte de génie du E-santé ; il y a créé plusieurs sites très actifs et enseigne « Médecine et Web 2.0 » à Debrecen.

D. Silber a insisté sur le fait que l'intelligence collective (collectivement construite), ça existe et c'est important. Selon elle, Web 2.0 en santé est utile de quatre manières au moins : entre professionnels et patients, aux professionnels entre eux, aux patients entre eux (voir la recherche gérée par eux), et entre patients et leurs proches.

Des réserves et craintes ? Un médecin de famille a réagi en disant qu'était absent de la présentation de ces « merveilles » le corps du patient, le contact direct et physique entre soigné et soignant. Avec raison. A l'évidence, le rapport humain, la « personal touch », ne sont pas au premier plan – mais ne sont pas forcément exclues non plus.

Il est exclu que le foisonnement d'activités électroniques en rapport avec santé et maladie, leur déterminants, les soins (y compris diagnostic et traitement), s'éteigne comme feu de paille. Il y a évidemment des risques à gérer, notamment du registre éthique : contrôle de qualité des sites ; apprentissage du tri dans des masses de données, pour les professionnels comme pour les laïcs

(le nettoyage y relatif des sites est dit *curation*) ; confidentialité (mais aujourd'hui certains exposent volontairement leur dossier médical sur les réseaux sociaux... et cela leur a permis parfois d'être aidés ; ainsi à propos de maladies rares).

Des enseignants universitaires présents ont souligné qu'il était essentiel que les médecins et autres professionnels abandonnent les réactions critiques qu'ils ont pu avoir quand un malade parle de ce qu'il/elle a trouvé sur internet. Ceci doit faire partie intégrante de la formation : apprendre à ne pas voir là méfiance ou dilution de responsabilités mais utiliser ces sources au bénéfice du soignant comme à celui du soigné. Web 2.0 en médecine et santé doit être enseigné au même titre que d'autres compétences indispensables, en cherchant le bon dosage entre méthodes d'enseignement classique et e-learning. Enfin, il y a là un champ de recherche en expansion rapide (cf. *Journal of Medical Internet Research*).

* Intéressant de noter cette nouvelle signification *relationnelle* de précautions universelles, terme utilisé d'abord pour des mesures très « matérielles » de protection en rapport avec les risques d'infections par les virus des hépatites ou du sida.

Jean Martin

Membre de la Commission nationale suisse d'éthique
La Ruelle 6, CH-1026 Echandens, Suisse

jean.martin@urbanet.ch

BOOK REVIEW

E. Sgreccia (Ed.). *Personalist Bioethics Foundations and Applications*, Translated by J. A. Di Camillo & M. J. Miller. Philadelphia: The National Catholic Bioethics Center, 2012, 838 pages, ISBN 978-0-935372-63-2

Among the most commonly used handbooks in Bioethics is the one edited by Cardinal Elio Sgreccia. This Handbook is published in two volumes, the first is the most important and essential because of its synthesis of the main principles and issues involved, it has been translated into 10 languages around the world. Now, for the first time, we have the opportunity to hold this masterpiece in our hands, freshly translated into English. Elio Sgreccia is the pioneer of Bioethics in Italy and also the founder of Personalist Bioethics in Italy and abroad. Personalist Bioethics has its roots in the philosophical traditions of Aristotelian and Thomistic perspectives which are synthesized in an ontologically grounded personalism. The intention the author has with this book is to give the audience a

systematic work as an introduction to the main problematic issues in Bioethics. The work was published in Italian in 1988 with the name *Bioetica: Manuale per medici e teologi*, in English *Bioethics: A Manual for Physicians and Theologians*. The first purpose of this book was to serve as a manual for the students at the Faculty of Medicine and Surgery, where Cardinal Sgreccia was the first to begin teaching Bioethics in Italy. Later the work was revised, updated and edited three times from 1994 to 2007.

The 2012 English edition of this handbook carries the name of the inspiration which informs the whole work. The book has two parts; the first is called *General Bioethics* and the second part *Particular Bioethics*. In the first part, which consists of seven chapters, the author speaks about the history of Bioethics, its development and the principles of Personalist bioethics with its roots in the philosophical tradition. Many wonder why there is a need to establish a new ethical perspective when we already have a lot of existing ethical perspectives. Wouldn't it be easier to accept an existing one? The main reason for the birth of this ethical perspective is the manipulation, in different ways, of the norms in existing ethical understandings. This perspective fortifies the objective basis of Bioethics which cannot be manipulated by those who have the power to change and create norms. This objective grounding is founded on values that are intangible and can not become the object of relativization; to these belong respect and protection of human life from its conception to its natural end. The second part, *Particular bioethics*, which consists of nine chapters, describes the application of the main principles to the most problematic current issues in medicine such as abortion, reproductive technologies, genetic testing, cloning, organ transplantation, euthanasia etc. The author resolves each of these topics with, what he calls a "triangular" method. His standpoint is that the scientific dimension represents only the descriptive aspect of reality and therefore there is a need for philosophical and anthropological dimensions which will clarify the truth, as well as the science of ethics which evaluates the moral dimension of acts. The physician acts properly only when all three components of the "triangular" method exist.

The book has been prepared in a systematic way, thus making it easily read by everyone. At the end of each chapter there is a short summary with the key notions, which are most important to repeat. In the Italian version the bibliography was at the end of each chapter; in this way it was easier for the reader to find and to deepen his knowledge of the topics through other sources. Instead of this, the English translation has a complete bibliography at the end of the book.

The primary aim of this book is to introduce the reader to Bioethics and its most problematic issues, especially to those who wish to deepen their knowledge. This handbook isn't compiled from different positions about problematic issues; on the contrary, the author takes a clear position without ambiguity, but he also speaks about other existing philosophical positions. According to him, the personalist position is valid because the personalistic philosophy is faithful both to science and to philosophical argumentation which is based on anthropology and the totality of man. Based on this philosophical tradition the author considers it fully legitimate to refer to the documents of the Catholic Church's Magisterium because it doesn't contradict personalist philosophy. Through reading of this book the reader will thus find references to the documents of the Magisterium of the Catholic Church as well.

This book was and remains today a very useful guide to the fundamental issues of Bioethics. Its features will be useful to a very wide range of readers, from professors of Bioethics, member of Ethics Committees, students, to laymen who want to familiarize themselves with the field of Bioethics.

Anto Čartolovni
Phd Fellow
Institute of Bioethics, Faculty of Medicine and Surgery,
Catholic University of Sacred Heart, Rome – Italy

anto.cartolovni@gmail.com

BOOK REVIEW

Justice, chance et responsabilité dans la santé et les soins

A propos de : Denier Y, Gastmans C, Vandeveldel A. *Justice, Luck & Responsibility in Health Care*. Dordrecht: Springer, 2013

La notion de chance, aux plusieurs sens de « bénéfique » (avoir de la chance), de probabilité (combien de chances que..) et de hasard, joue un rôle majeur dans les débats traitant de santé, d'assurance-maladie, de contrainte à cet égard (couverture universelle), de responsabilité des pouvoirs publics. Ceci aussi bien dans la réflexion et l'action des citoyens individuels que dans celles des gouvernements et parlements.

Justice, Luck & Responsibility in Health Care, publié sous la direction de trois philosophes-éthiciens de l'Université de Louvain/Leuven, restitue les exposés d'une conférence tenue en mai 2011. Les 12 auteurs sont des enseignements universitaires en philosophie et éthique ; trois d'entre eux ont aussi une formation

théologique et trois autres incluent de manière marquée l'économie et la science politique dans leurs travaux.

La « naturel » n'est plus comme auparavant un donné, on peut agir sur lui – ce qui implique des prises de responsabilité

Yvonne Denier explore les questions de justice et responsabilité en rapport particulièrement avec le diagnostic génétique prénatal. Elle cite Buchanan et al. (les citations qui suivent sont de ma traduction): « A mesure que les possibilités d'interventions génétiques sur des êtres humains deviennent plus proches d'être concrétisées, nous serons probablement forcés d'élargir radicalement notre conception de la justice sociale, en incluant des attributs *naturels* aussi bien que sociaux parmi les biens que des institutions justes doivent réguler/distribuer équitablement ». Ces auteurs parlent de la « colonisation du naturel par le juste ».

Denier relève que, aujourd'hui, nos caractéristiques naturelles ne sont plus comme auparavant une pure question de chance (*brute luck*). Cela fait « repenser des postulats fondamentaux sur les relations entre justice, nature humaine et progrès moral » ; entre autres le postulat que « les résultats de la loterie naturelle dépendent strictement de la chance et ainsi échappent à notre responsabilité morale ».

Dans sa contribution, Vandeveldel évoque une question très délicate mais dont il serait surprenant qu'elle ne soit pas posée de plus en plus souvent : « Aujourd'hui déjà le diagnostic génétique prénatal permet de prédire des déficiences chromosomiques de l'enfant à naître. Est-ce que la justice égalitaire demandera de maintenir une solidarité avec des parents qui, le sachant et le voulant, choisissent de donner naissance à un enfant handicapé ? ». On peut s'interroger de manière comparable sur les parents refusant de faire vacciner leurs enfants, ou ceux qui sciemment les soumettent à d'autres risques évitables.

Démence et directives anticipées

Thomas Nys développe une réflexion sur les places respectives de ce qu'on appelle *critical interests*, à savoir ceux qui apparaissent dans les directives établies alors que le patient avait le discernement, et *experiential interests*, ceux que la personne démente manifeste sur le moment – dont au reste l'interprétation n'est pas aisée. Il discute le rôle des proches : « Nous avons généralement une bonne idée de qui sont les personnes importantes pour le patient (*significant others*). Les membres de la famille ont déjà voix au chapitre dans le traitement de leurs proches. Mon intention était de prendre du recul par rapport au soupçon fréquent à leur sujet, parce qu'ils ne seraient

pas de bons interprètes des désirs du patient ou parce qu'ils seraient influencés par leur propres intérêts, et par conséquent qu'on ne saurait leur faire confiance ». A l'évidence, il n'y a pas ici de recette valable dans tous les cas et cela sollicite des appréciations fines des soignants ; mais, mon sens (J. M.), il convient d'être attentif à ne pas restreindre/négliger l'autonomie du malade telle qu'elle est exprimées dans les directives.

A cet égard, cette expérience souvent vécue : « Mon mari [souffrant de démence] n'est plus l'homme que j'ai épousé. Ce dernier est mort depuis deux ans ». En deçà des grandes questions philosophiques, comment contester que cela corresponde à une réalité dans la vie de l'épouse ?

Rationnement, devoir de mourir (!)

Les ressources sont toujours en quantité limitée, on le sait bien, mais la notion de rationnement reste largement frappée d'anathème dans nos pays. Pourtant, n'est il pas souvent vrai, comme le dit Martin Gunderson, que « si un gouvernement ne développe pas de politique de rationnement, la distribution de ressources rares et onéreuses en matière de soins sera réalisée par d'autres moyens, comme la couverture par des assurances privées ou la capacité propre de payer ».

John Hardwig est un philosophe américain auteur de plusieurs articles engagés sur le « devoir de mourir » dans certaines situations (plus fréquentes aux Etats-Unis où il est courant d'être ruiné par le coût des soins). A son avis, même s'ils sont substantiels (comme en Europe), « les filets de sécurité sociale institutionnels ne couvriront jamais toutes les difficultés que peuvent rencontrer les familles et les proches d'un malade. Pour cette raison, les dispositions collectives n'élimineront jamais le nécessité de faire face de manière responsable à la fin de sa propre vie » (à savoir, dans l'esprit de l'auteur, d'admettre parfois le devoir de s'en aller). Ajoutant : « Si cela semble horrible, je peux seulement inciter chacun d'entre nous à se souvenir que le devoir de mourir n'est que l'autre face de la meilleure santé et des vies plus longues dont nous sommes privilégiés de bénéficier ».

Les maladies infectieuses, sujet classique de santé publique

« Dans la mesure où la transmission des maladies infectieuses peut être liée à la sphère privée des citoyens, les mesures prises par les autorités de santé publique vont souvent entrer en conflit avec la protection des libertés civiles » (Jeroen Luyten). Et plus loin : « Pour réduire l'incidence de ces maladies de la manière la moins controversée, les autorités

devraient pouvoir compter largement sur le coopération des citoyens ». Et un rappel utile : « le niveau souhaité/requis de prévention dépendra de la valeur accordée à la santé de la population par rapport à d'autres objectifs sociétaux qui devraient cas échéant être sacrifiés »

Donner suffisamment attention au contexte sociétal

Les interrogations ci-dessus dépendent de ce que les uns et les autres nous appelons une vie vraiment humaine. H. De Djin à ce sujet: « Est-ce que cela consiste à avoir eu un certain nombre d'années de vie d'une certaine qualité ? Est-ce qu'une bonne vie est d'avoir vécu des expériences de diverses sortes ? Ou une vie véritablement humaine doit-elle être jugée de manière holistique, selon la réalisation de fins ou buts supérieurs ? Dans ce cas, cela signifie-t-il que la valeur d'une vie ne peut être déterminée que dans le contexte d'une reconnaissance par d'autres ? Qu'entendons-nous exactement en disant que les humains sont des êtres relationnels ? [Mitsein] ». Bonnes questions.

Citation de l'épilogue du livre, par Paul Schotsmans, personnalité senior de la bioéthique belge : « Bien trop longtemps, les bioéthiciens ont négligé le devoir de situer les responsabilités et les défis dans le contexte des systèmes et politiques de santé, au plan national et international. Progressivement toutefois, ils ont commencé à regarder au-delà de leur micro-contexte et à intégrer les enjeux sociétaux. Personne ne vit seul. Personne ne naît comme une page strictement blanche. Nous sommes tous des êtres humains situés (...) Si nous n'incluons pas les débats dans le contexte sociétal, même s'agissant de choix qui semblent purement privés, nous agissons comme si nous étions des êtres surnaturels ».

En résumé, un ouvrage substantiel sur des sujets d'actualité, tant les questions de justice, de dignité, d'autonomie de la personne et de devoir de s'assumer, du rôle nécessaire (et suffisant ?) des pouvoirs publics dans les soins et le système de santé, vont continuer à être très présentes et très discutées. Et controversées dans la mesure où chacune de ces notions reçoit des définitions diverses selon le mode de raisonnement et les fondements philosophiques et sociaux des experts et des politiques qui s'expriment.

Jean Martin

Membre de la Commission Nationale Suisse d'Éthique
La Ruelle 6, CH-1026 Echandens

jean.martin@urbanet.ch

NEW ASSOCIATE MEMBER

The Southwest State University
Professor E. Sergey
50 let Octiabrya str. 94, Kursk
305040
RUSSIA

esg@kstu.kursk.ru

<http://www.swsu.ru>

EACME PRIZES

The European Association of Centres of Medical Ethics awarded two EACME-prizes of 500 Euros.

The EACME prizes were awarded to:

Caroline Brall

Institut für Medizinische Ethik und Geschichte der
Medizin Ruhr-Universität Bochum
Malakowturm, Markstr. 258a
44799 Bochum
Germany

for her scientific contribution "*Personalised Medicine and Public Health. An Ethical Account on the Basis of Public Health Ethics Frameworks*".

Marco Annoni

Campus IFOM-IEO
Via Adamello 16
Milan 20139 ITALY

for his scientific contribution "*Integrating Personalized Medicine and Person-Centred Medicine: Lessons and Directions from the Recent Search for Biomarkers of Placebo Response*".

This was the result of a fully blind review procedure within the Daily Board of EACME.

Our President, Professor Renzo Pegoraro, will present the EACME prize officially during the conference in Bochum.

Congratulations to both EACME-prize winners!

DEADLINE NEXT NEWSLETTER

Deadline for the second edition of 2013:

August 15, 2013

If you wish to promote an event, or to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc. Any good ideas?

Don't hesitate to contact editor Rouven Porz: rouven.porz@insel.ch or Angelique Heijnen : a.heijnen@maastrichtuniversity.nl

ANNOUNCEMENTS

Annual EACME Conference

19 – 21 September, 2013 (Bochum, Germany).

The main topic is: 'Personalised medicine' – medicine for the person? Ethical challenges for medical research and practice. Subtopics: Patient as person in medicine, Research in 'personalised medicine', Clinical practice and Healthcare systems.

The Institute for Medical Ethics and History of Medicine, directed by Prof. Dr. med. Dr. phil. Jochen Vollmann, Ruhr University Bochum will be EACME's host.

For further information, please visit the conference website: <http://www.eacme2013.org>

Australasian Association of Bioethics & Health Law Conference 11 - 14 July 2013, Sydney University Law School (Australia)

For further information, please visit the website: <http://www.cdesign.com.au/aabh2013/>

27th ESPMH Conference Basel Switzerland
"Innovation in Health Care and the Life Sciences"
14 – 17 August, 2013

For further information, please visit the website: <http://www.espmh.org>

UNESCO Chair in Bioethics 9th World Conference BIOETHICS, MEDICAL ETHICS & HEALTH LAW Towards the 21st Century

Royal Continental Congress Center
Naples, Italy

November 19-20-21, 2013

For further information, please visit the website: www.isas.co.il/bioethics2013

NURSING ETHICS

Intensive Course on Foundational Approaches, Contemporary and Educational Issues in the Field of Nursing Ethics

Date & Location:

Leuven, Belgium, 3-6 December 2013

Organised by: Erasmus Mundus Master of Bioethics
Centre for Biomedical Ethics and Law
Faculty of Medicine Katholieke Universiteit Leuven,
Belgium

Coordinator: Chris Gastmans, PhD
Keynote Speaker: Per Nortvedt, PhD, RN
Chair, Centre for Medical Ethics,
University of Oslo, Norway

Objectives: The objective of the course is to foster exchanges on foundational and methodological approaches as well as on contemporary and educational issues in nursing ethics.

Format: This course works from an interdisciplinary (philosophical, theological, nursing, clinical-ethical) perspective. During the course, national and international experts will give presentations on various topics in the domain of nursing ethics.

Participants: The course is of interest to participants from diverse professional backgrounds, such as nursing, medicine, philosophy and theology, health care administration, and PhD students undertaking courses of study in these areas. The intensive course Nursing Ethics is part of the Erasmus Mundus Master of Bioethics programme organised by a consortium of three European universities, namely the Katholieke Universiteit Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and the Università degli Studi di Padova (Italy). Because of this combination, participants of the intensive course Nursing Ethics, will join Master students from all over the world.

Price: The course fee will be € 775 if you register as a participant before October 15th 2013, € 875 for registration from October 15th 2013 onwards. This fee includes tuition and course materials, as well as refreshments, four lunches, a dinner and a concert in the Concert hall of Bruges. Detailed information on registration and payment can be found at our website www.masterbioethics.org under Intensive Courses.

Information:

Chris Gastmans PhD and Chantal De Keersmaecker
KU Leuven: Centre for Biomedical Ethics and Law
Kapucijnenvoer 35/3 box 7001
3000 Leuven Belgium

E-mail: Chantal.dekeersmaecker@med.kuleuven.be

www.masterbioethics.org

EDITORIAL BOARD

Rouven Porz, Editor

Ethics Unit
Direktionspräsidium, Bern University Hospital
"Inselspital"
CH – 3010 BERN SWITZERLAND
rouven.porz@insel.ch

Alessandra Bernardi

Fondazione Lanza
Via Dante, 55
35139 PADOVA ITALY
alessandra.bernardi@ioveneto.it

Caroline Brall

Abteilung für Medizinische Ethik und Geschichte der
Medizin, Ruhr-Universität
Malakowturm - Markstr. 258a
D-44799 Bochum GERMANY
caroline.brall@ruhr-uni-bochum.de

Jean-Philippe Cobbaut

Université Catholique de Lille
Centre d'Éthique Médicale
56, rue du Port
F-59046 LILLE Cedex FRANCE
jean-philippe.cobbaut@icli-lille.fr

Angelique Heijnen

Maastricht University
FHML, Health, Ethics and Society
P.O. Box 616
6200 MD MAASTRICHT THE NETHERLANDS
a.heijnen@maastrichtuniversity.nl

Jeanette Hewitt

Swansea University
Department of Philosophy, History & Law
School of Health Science
Singleton Park SWANSEA
South Wales SA2 8PP UNITED KINGDOM
j.l.hewitt@swan.ac.uk

Elleke Landeweer

Department of Medical Humanities, VUmc
P.O. Box 7057
1007 MB AMSTERDAM THE NETHERLANDS
e.landeweer@vumc.nl

Jean Martin

La Ruelle 6
CH- 1026 ECHANDENS SWITZERLAND
jean.martin@urbanet.ch