

25 YEARS OF THE BELGIAN ADVISORY COMMITTEE ON BIOETHICS
BIENNIAL CONFERENCE

autonomy revisited

28 AND 29 APRIL 2021

On Wednesday 28th and Thursday 29th April 2021, the Belgian Advisory Committee on Bioethics is organising its XII Biennial Conference themed “Autonomy Revisited”. It will also be an occasion to celebrate **the Committee’s 25th Anniversary**.

This conference will take place in the form of a webinar and will be interactive. It is aimed at the **wider public**, as well as at **healthcare professionals**. Participation at the conference is free but registration is required. Accreditation for physicians and pharmacist-biologists has been granted (‘ethics and economics’; 28/4 = 3 C.P.; 29/4 = 6 C.P.).

During these days, you will be able to attend the following sessions, which also include Q&A sessions.

wednesday 28th april

ACADEMIC SESSION

- 15.30** Opening by Mr Paul Cosyns,
Vice-Chairman of the Committee
- 15.45** Official addresses
- 16.00** Introduction by Mrs Florence Caeymaex,
Committee Chairwoman
- 16.30** Mrs Margaret Lock
(Professor Emerita, Mc Gill University, Canada)
« **Permeable Bodies and Toxic Environments** »
- 17.30** Mrs Dominique Memmi
(Head of research at the CNRS in social sciences, France)
« **“Manufacturing” the subject: The carers’ own contribution (since the 60ies, in France)** »
- 18.30** Closing word

thursday 29th april

CONFERENCE DAY WITH INPUT OF STUDENTS

- 9.15** Welcome by Mrs Florence Caeymaex,
Committee Chairwoman
- 9.30** Mr Nicolas Marquis
(Professor at UC-Louvain Saint-Louis in Brussels, ERC
Starting Grantee)
« **Doing what's right for others in spite of themselves?
Revisiting autonomy in psychiatric and mental health
care** »
- 10.20** **Presentation by student group 1** : section *Art-Therapy*
at the *Institut Ilya Prigogine* in Brussels, under
supervision of Mrs Marie-Françoise Meurisse
- 11.00** **Break**
- 11.20** **Presentation by student group 2** : 3rd and 4th year *Nursing*
and *Ergotherapy* at *PXL-Hogeschool Hasselt*, under
supervision of Mr Jan Coel and Mrs Katrien Ruytjens
- 12.00** **Break**
- 13.00** **Presentation by student group 3** : international master
in *Public Health Methodology* (ULB), under supervision of
Mrs Sarah O'Neill and Mrs Katia Castetbon
- 13.40** **Presentation by student group 4** : master in *Public
Health Sciences* (Uliège), under supervision of Mrs
Florence Caeymaex and Mr Benoît Pétré
- 14.20** **Break**
- 14.40** **Presentation by student group 5** : 3rd year *Nursing* at
Erasmushogeschool in Brussels, under supervision of
Mrs Ingeburg Digneffe in cooperation with Mr Julien
Libbrecht
- 15.20** Mrs Jeannette Pols
(Professor Dr., University of Amsterdam, Netherlands)
« **Autonomy in practice. From abstract principles
towards everyday life ethics** »
- 16.10** **Closing word**

more on the theme “autonomy revisited”

Three caring sisters work together with caregivers to allow their mother, suffering from Alzheimer’s disease and who is still doing well enough, to be able to stay at home, but end up having to take away her keys and lock her in her own home, due to repeated and dangerous instances of running away (Hennion & Vidal-Naquet, 2015).

A terminally ill patient with metastatic lung cancer requests euthanasia but, in the ward where he is treated, no one feels able to respond to his request because all are close friends and his wife, a nurse in this team, cannot bear the thought of helping her husband to end his life.

A young man in his twenties who has been diagnosed with cancer, and who is a drug and alcohol user, irritates the nursing staff because he will not follow his treatment or keep his medical appointments.

A young woman, contemporary dancer and creator of the Huntington studio, Handicap and Dance, for people suffering from this disease, learns along the way that she is herself a carrier; she refuses to be informed about her illness, but chooses to deepen her understanding through dance and the other patients and thereby ends up gaining the confidence she lacked in the meaning of her profession (Hermant et al., 2017).



A doctor wonders whether or not to speak about organ donation to a patient affected by a neuroevolutionary condition who has just requested euthanasia and did not happen to think of it him/herself.

A pregnant mother of two knowing her foetus is at risk of Down’s syndrome after a genetic test, chooses with the father of this child not to proceed with the second examination, thus foregoing a diagnosis.

A husband is taking care of his dependent wife and defers the support offered to him, at the risk of losing his health, because he wants to remain faithful to their happiness of being together.

A disabled person now manages her allowances herself and chooses which services she needs.

So many situations, familiar in the area of support and care today, which involve autonomy, or more precisely the *ideal* of autonomy held by biomedical ethics since its beginnings. How can unique cases and situations define our views of this notion?

Historically, ethical reflection, together with the progressive development of legal frameworks for biomedicine, has predominantly focused on human rights; it has made respect for autonomy a paramount principle. The importance given to free and informed consent, as well as to the free choice of every person to define their own values and lifestyle reflects a tendency to identify individual autonomy as the freedom of independent, rational and strategic subjects, capable of expressing and achieving personal preferences, without outside intervention. It has swayed ethics to seek, as a priority, regulations that safeguard this autonomy as much as possible in terms of the powers inherent in biomedical knowledge and practices, the State, market mechanisms or even communities of belonging (Callahan, 2012).

But attention to experiences - of patients, doctors, relatives, carers - reminds us that, in the field of disability, old age, dependence, and illness, autonomy is not a given, but something to be pursued: a goal that must be *identified*, precisely because it ceases to be self-evident (Hennion et al., 2012). It also teaches us that people, sick or not, dependent or not, are always linked or «at-

tached» - to families, cultures or languages, habits, ways of being and living, places, objects: to everything that matters to them, good or bad (Latour, 2000; Hache, 2011). So many links of interdependence in which their power to act and want is bound, and from which «autonomy» first means «dealing with»: coping as well as possible with an always unique situation, here and now.

This attention to experiences and the uniqueness of situations is familiar to many healthcare workers, in particular those for whom ethics is first and foremost about working on ways to do and act on a daily basis. But this type of attention also belongs to the humanities and the arts; investigating, telling, following the twists of a story, addressing the details of a situation, exploring its constraints and possibilities, and taking into account the circumstances are all modes of knowledge in their own right.

On the occasion of its 25th anniversary, the Belgian Advisory Committee on Bioethics intends to explore, with regard to autonomy, the possibilities that the alliance of medical knowledge and practices with the humanities and the arts can offer to ethical reflection. At a time when many are trying to theoretically define “relational autonomy” (Gastmans, 2019), we are seeking to show how, where specifically *put to the test*, autonomy is identified, invented in practice, and redefined by its uses, in everyday links. The methods of the humanities and the arts probably do not give us an unambiguous and general definition, nor do they tell us what autonomy should be. But they can, on the other hand, broaden the scope of its possible

meanings and thus increase our repertoire of action - a necessity, if the fundamental role of ethics remains, not to establish definitive rules, but to question the way we do and act, to make this as fair or as good as possible and “to be ready to revise our conclusions day by day” (James, 2005).

Bibliography

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