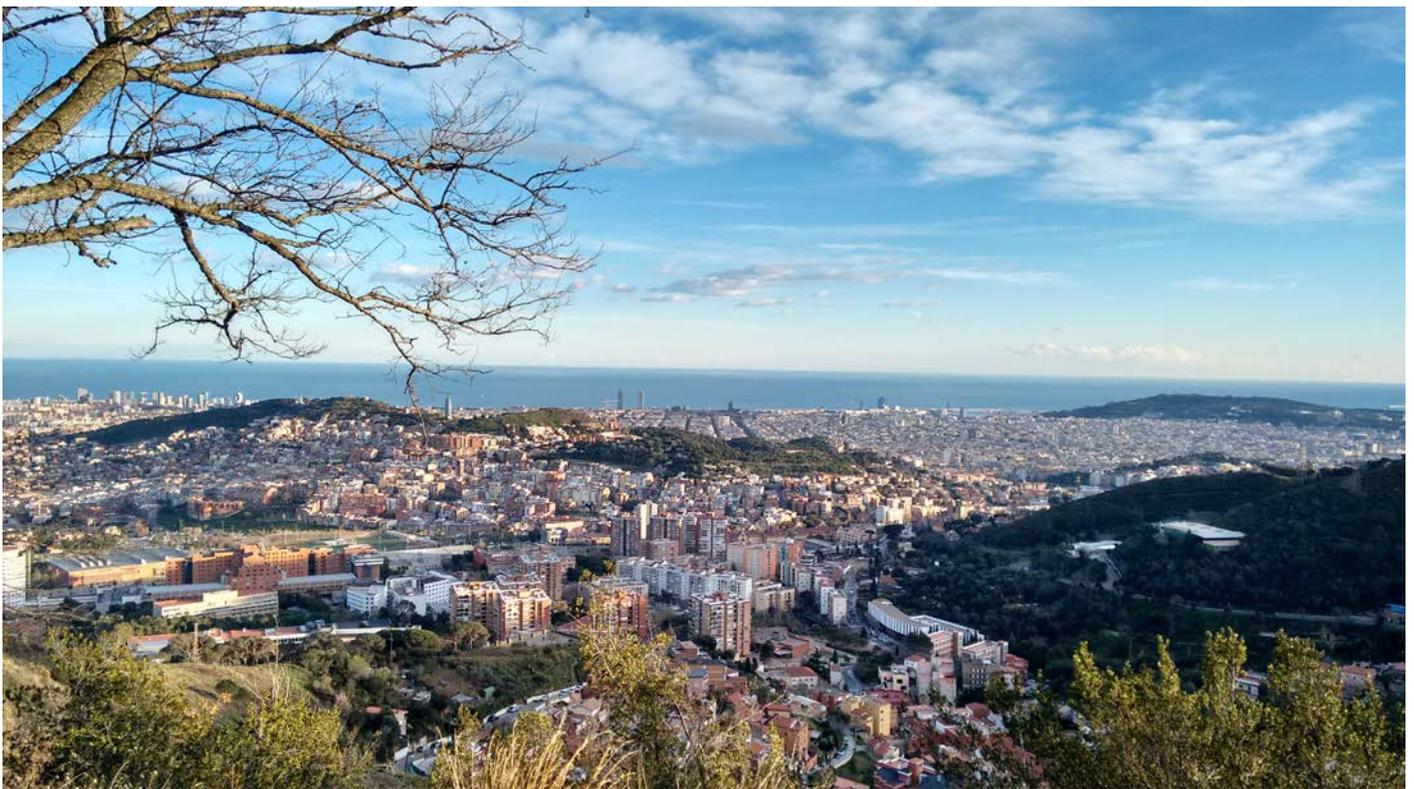


2017 EACME Annual Conference  
***“Justice in Health Care – Values in Conflict”***

September 7-9, 2017  
Barcelona



**CONFERENCE BOOK**



# Welcome to Barcelona

Both the European Association of Centres of Medical Ethics (EACME) and the Borja Institute of Bioethics-Ramon Llull University (Barcelona) organize the 2017 EACME Annual Conference.

The European Association of Centres of Medical Ethics (EACME) is, since its creation in December 1986, an international research and communication network with the aim to promote research, education and consultation in the field of (bio)-medical ethics.

The Borja Institute of Bioethics-Ramon Llull University (Barcelona) was founded in 1976 with the main goal of studying in depth the problems raised by progress in biomedical science and its implications for society and its values, disseminating its findings in specialized publications.

Recent developments in several countries in Europe, such as austerity measures, lead to concerns about the conflict between justice in health care with other economic and political values. That is why the Programme of 2017 EACME Annual Conference, under the topic “**Justice in Health Care – Values in Conflict**”, focuses on the following important issues:

- Determinants of Health
  - What does health mean? Looking beyond WHO definition
  - Lifestyles and health
  - Quality of life
  - Social expectations and medicalisation of life
  - *Salutogenesis* and health-promotion activities
- Healthcare Systems: at the Service of What?
  - Ethical issues in different models of Healthcare Systems
  - Sustainability
  - The role of Primary Care in health systems
  - Ethics issues in research with big data
  - Designing future healthcare systems
- Justice and Vulnerability
  - Social inequalities in health
  - Mental health care
  - Care for people with disability
  - Childcare, Elderly care
  - End-of-life care

- The Role of Professionals and Research
  - Professionalism and decision-making
  - Effects of austerity measures on health care
  - Quaternary prevention
  - The clinician as a manager of resources
  - Continued education
  - Responsibility and integrity in research

We are wishing to discuss about all these important questions with you.  
Welcome to Barcelona!

**Margarita Bofarull Buñuel**  
President of the Scientific Committee

**Montserrat Esquerda Aresté**  
President of the Organizing Committee

# The Borja Institute of Bioethics

The Borja Institute of Bioethics started in 1976 with Dr Francesc Abel, S.J., doctor in Medicine and Surgery, specialist in Obstetrics and Gynaecology, and masters degree in both Philosophy and Theology. Dr Abel started his investigation in the United States of America at the precise time when Bioethics became a discipline. When he came back to Europe he had the immediate and lucid insight to create the first Bioethics institute in the Old Continent, task in which he was backed by the Society of Jesus, and later by the Hospitaller Order of Saint John of God. In 2000, the centre was incorporated into the Universitat Ramon Llull as a university institute.

The Borja Institute of Bioethics main aim is to study in depth problems raised by progress in biomedical science and its implications for society and its values. In addition, the Institute encourages interdisciplinary dialogue between scientists and humanists as a means to integrating scientific knowledge and ethical sensibility and finding appropriate ways to solve the problems arising from conflicts between technical views of reality and the cultural and social values which are essential in any discussion of human rights.

The human team of the Institute is formed by professionals of different disciplines and expertise, from the Medicine, Philosophy, Theology, Law and Social Science. Most part of the Borja's team share the bioethics dedication with its own professional scope.

The main activities of the institute are education, research and assessment in bioethics.

## Education

The Institute offers a University Master's degree in bioethics (12 edition) that aims to promote reflection and research on ethical issues related to human life and the value conflicts often generated by advances in medical science and technology. Progress in genetics, the beginning of life, health care priorities, patient rights, public health, organ transplants, AIDS, degenerative diseases or disabilities, the limits of treatment, or end-of-life decisions, are just some of the issues it addresses.

These studies aim to provide professionals with a solid training required to be able to identify and clarify the main problems raised by human life and health care from an ethical standpoint. Professors representing a variety of disciplines — philosophy, human rights, health sciences and law— will provide both theoretical and practical guidance. Also, two Courses of University Experts are offered by

the Institute: an University Expert Course based in Clinical Ethics and another University Expert Course in Social Ethics. And we also offer a basic bioethics training, an Intensive Course on Ethics and good Clinical Practices, and Up-date or monographic courses.

## Research

The Borja Institute Research activity is organized around four main lines:

1. *Ethical criteria for the distribution of resources: rethinking Public Health Systems.* In Western countries, the demand for health services is growing at a faster rate than the available resources. Chronic disease, population age, biotechnological development, social changes, the risk of over diagnosis and overtreatment are some of the issues.
2. *Moral development, empathy and burnout in medical and health students and health professionals.* The physician's and health professionals' ethical development plays an important role in quality healthcare, patient safety, and in patient's quality of life. The aim of this line is how health professionals and students develop ethical competence, and the relationship with empathy or burnout.
3. *Health decision in children and adolescents. Assessment of the minor's competence for decision-making in health and research.* The participation of children and adolescents in healthcare processes is a new challenge. Not only does it require a change of attitudes towards minors but also acquiring knowledge and skills to be able to develop shared decision-making and information processes. In this context, it is therefore crucial to develop an assessment of the minor's competence that can be easily corrected and applied within the normal time frame of a clinical consultation.
4. *Ethical aspects at the end of life.* The Institute participates in a multi-centre project on end-of-life, as well as in some projects on training in attitudes about death and mourning, and fear of death.

The Institute also publishes the journal *Bioetica & Debat*, and co-publishes the *Revista Iberoamericana de Bioética* and the *Ramon Llull Journal of Applied Ethics*.

## Assessment

The Institute has been of big importance in the creation of the first Healthcare Ethics Committee (HEC) in Spain: the one at Hospital Sant Joan de Déu in Esplugues de Llobregat (Barcelona). It has also helped in the creation of other HEC and belongs to various HEC and Human Research Ethics Committees.

After more than 40 years of existence, the Borja Institute of Bioethics continues being faithful to the idea of his founder, which means faithfulness to academic and scientific rigour, to the spirit of dialogue and compromise with society in accordance with our present time, with a scope of positivism towards the future. The search for academic formation, the results of investigation towards society, innovation and assessment, in cooperation with centres and institutes dealing with the field of Bioethics around the world, will define our way in years to come.



# Organization

The 2017 EACME Annual Conference is organized by the European Association of Centres of Medical Ethics (EACME) and the Borja Institute of Bioethics-Ramon Llull University (Barcelona).

## Honorary Committee

**Mr Antoni Comín i Oliveres** - Minister of Health of the Generalitat de Catalunya, Catalan Government

**Br José Luís Fonseca Bravo** - Superior Provincial of Aragón-Sant Rafael Province of the Hospitaller Order of Saint John of God

**Dr Llorenç Puig i Puig** - Delegate of Catalonia Territorial Platform of the Society of Jesus

**Dr Josep Maria Garrell i Guiu** - Rector Magnificus of Ramon Llull University, Barcelona

**Dr Joan Planellas i Barnosell** - Dean of the Faculty of Theology of Catalonia

**Dr Ruud ter Meulen** - President of the European Association of Centres of Medical Ethics

**Dr Josep A. Bombí i Latorre** - President of the Royal Academy of Medicine of Catalonia

**Dr Victòria Camps Cervera** - Universitat Autònoma de Barcelona Emeritus Professor of Moral Philosophy and Politics

**Dr Javier de la Torre Díaz** - Director of the Chair in Bioethics of the Comillas Pontifical University

**Dr Juan María de Velasco Gogenola** - Assistant Professor of Theology of the University of Deusto

## Scientific Committee

**Margarita Bofarull** (chair) - Borja Institute of Bioethics – Ramon Llull University

**Ester Busquets** - Borja Institute of Bioethics – Ramon Llull University

**Juan Antonio Camacho** - Borja Institute of Bioethics – Ramon Llull University

**Francisco J. Cambra** - Borja Institute of Bioethics – Ramon Llull University

**Maria Casado** - University of Barcelona

**Jordi Craven-Bartle** - Borja Institute of Bioethics – Ramon Llull University

**Victoria Cusí** - Borja Institute of Bioethics – Ramon Llull University

**Montserrat Esquerda** - Borja Institute of Bioethics – Ramon Llull University

**Pau Ferrer** - Borja Institute of Bioethics – Ramon Llull University  
**Ruth Horn** - University of Oxford  
**Ruud ter Meulen** - University of Bristol  
**Eva Peguero** - Catalan Society of Family and Community Medicine  
**Rouven Porz** - University of Bern  
**Josep Ramos** - Borja Institute of Bioethics – Ramon Llull University  
**Bernabé Robles** - Borja Institute of Bioethics – Ramon Llull University  
**Helena Roig** - Borja Institute of Bioethics – Ramon Llull University  
**Begoña Roman** - Borja Institute of Bioethics – Ramon Llull University  
**Mar Rosàs** - Blanquerna. Ramon Llull ETHOS Chair – Ramon Llull University  
**Núria Terribas** - Víctor Grifols i Lucas Foundation  
**Francesc Torralba** - Ramon Llull ETHOS Chair – Ramon Llull University  
**Joan Viñas** - Borja Institute of Bioethics – Ramon Llull University

## **Organizing Committee**

**Montse Esquerda** (chair) - Borja Institute of Bioethics – Ramon Llull University  
**M José Abella** - Borja Institute of Bioethics – Ramon Llull University  
**Anna Alonso** - Borja Institute of Bioethics – Ramon Llull University  
**Joan Bertran** - Borja Institute of Bioethics – Ramon Llull University  
**Margarita Bofarull** - Borja Institute of Bioethics – Ramon Llull University  
**Josep M Busquets** - Catalonia Bioethics Committee – Catalan Government  
**Ester Busquets** - Borja Institute of Bioethics – Ramon Llull University  
**Noelia Carro** - Borja Institute of Bioethics – Ramon Llull University  
**Sabel Gabaldón** - Borja Institute of Bioethics – Ramon Llull University  
**Angelique Heijnen** - Maastricht University  
**Laura Martínez** - Sant Joan de Déu School of Nursing – University of Barcelona  
**Ana Merino** - Sant Joan de Déu Research Foundation  
**Jesús Pineda** - Sant Joan de Déu Research Foundation  
**Helena Roig** - Borja Institute of Bioethics – Ramon Llull University

## **Cooperates**

Ministry of Health of the Generalitat de Catalunya, Catalan Government

# Contents

<b>Keynote sessions</b>	<b>1</b>
The normative significance of social determinants of health ( <i>Thomas Schramme</i> )	1
Health Care Systems – At the Service of What? ( <i>Yvonne Denier</i> ) . . . . .	2
Justice and vulnerability ( <i>Begoña Román-Maestre</i> ) . . . . .	3
Round table. Quaternary Prevention(P4) or first do not harm ( <i>Marc Jamouille, Patrick Ouvrard, Daniel Widmer, Ricardo La Valle &amp; Miguel Pizzanelli</i> ) . . . . .	4
<b>Oral Communications</b>	<b>7</b>
Relationship between science and ethics in Argentina: science with consciousness ( <i>Silvina Ávila, Paula Sánchez Thevenet, Pasqual Gregori Roig, Monica Souto, Cristian Silva &amp; Andrea Maza</i> ) . . . . .	7
Pediatric palliative care decision making in Switzerland ( <i>Elaine Acheson, Michael Rost, Nadia Pacurari, Bernice S. Elger &amp; Tenzin Wangmo</i> ) .	8
Ethics of deemed consent: The new Welsh approach to organ procurement and the role of the family ( <i>Andreas Brøgger Albertsen</i> ) . . . . .	9
Ethical aspects of preventive activities in general practice in Bulgaria ( <i>Silviya Aleksandrova-Yankulovska &amp; Toni Vekov</i> ) . . . . .	10
Personnel’s rights in provision of palliative care in Bulgaria ( <i>Silviya Aleksandrova-Yankulovska, Nikolai Yordanov &amp; Maria Kostova</i> ) . . . . .	11
Towards patient empowerment in Saudi Healthcare: The place of a Positive Patients’ Rights Culture ( <i>Faisal Almutairi, Ray Kirk &amp; Pauline Barnett</i> ) . . . . .	12
Top Four Ethical Issues in Romanian Healthcare System ( <i>Maria Aluas</i> ) . .	13
“Striking a Balance”: Could a mandatory medical practitioner reporting scheme of intimate partner violence be legally and ethically justified ( <i>Raj Amarnani</i> ) . . . . .	14
Who has the right to justify euthanasia? ( <i>Atanas Anov &amp; Silviya Aleksandrova-Yankulovska</i> ) . . . . .	15
La enseñanza de la Bioética: una contribución al perfil de egreso de los estudiantes de Medicina ( <i>Carmen Astete &amp; Lorna Luco</i> ) . . . . .	16
Blameworthy actions? On the anatomy of health-related actions people could reasonably be held responsible for ( <i>Kristine Bærøe, Andreas Brekke Carlsson, Andreas Brøgger Albertsen &amp; Cornelius Cappelen</i> ) .	17

Equitable healthcare: On the potential impact of politicization, bureaucratization and medical standardization of healthcare distribution on social health inequality ( <i>Kristine Bærøe, Inger Lise Teig &amp; Benedicte Carlsen</i> ) . . . . .	18
Conceptualizing health to reduce health inequality ( <i>Kristine Bærøe &amp; Berit Bringedal</i> ) . . . . .	19
Ethics of full disclosure in the presence of presumable placebo effects ( <i>Juan Pablo Beca</i> ) . . . . .	20
Sociotechnological background of personalized medicine development: better life for better humans? ( <i>R.R. Belyaletdinov</i> ) . . . . .	21
Surgeons and research: the context and concept of surgical innovation (1) ( <i>Giles Birchley, Richard Huxtable, Jon Ives, Noah Howes &amp; Jane Blazeby</i> ) . . . . .	21
Ethics recommendation for the big data's managing for a population-based health monitoring project ( <i>Luciana Caenazzo &amp; Pamela Tozzo</i> ) . . . . .	23
How are we making a crucial decision? A Reflective Judge's reprise ( <i>Andrea Castagnoli</i> ) . . . . .	24
An ethical approach to ER Facilities in Turkey for Syrians Under Temporary Protection ( <i>Orcun Cil, Sefik Gorkey &amp; Kursat Epozturk</i> ) . . . . .	25
La prescripción en Atención Primaria de Salud y la sostenibilidad de sistemas sanitarios ( <i>M<sup>a</sup> Constanza Colchero Calderón</i> ) . . . . .	25
No Health without Mental Health. Broadening the Scope of Bioethical Inquiry. ( <i>Paolo Corsico</i> ) . . . . .	27
Undoing Capacity: Applying the Capability Approach to Pediatrics ( <i>Eva De Clercq &amp; Bernice Elger</i> ) . . . . .	28
How to realize dignified care for female Islamic patients? A qualitative study of intercultural care experiences in maternity care units in Flanders, Belgium ( <i>Liesbet Degrie, Chris Gastmans, Bernadette Dierckx de Casterlé &amp; Yvonne Denier</i> ) . . . . .	29
From clinic to community: Teaching, supporting and doing ethics in care work outside hospitals ( <i>Michael Dunn</i> ) . . . . .	30
Beyond recovery: towards rights-based mental health care ( <i>Francisco José Eiroa-Orosa</i> ) . . . . .	31
Gender, equality and the steepness of the social gradients in health ( <i>Carina Fourie</i> ) . . . . .	32
Egg-freezing for age-related reasons: social expectations versus medicalisation of life ( <i>Véronique Fournier &amp; Laurence Brunet</i> ) . . . . .	33
Restorative Justice and Vulnerability in Medical Malpractice ( <i>Susan Fox</i> ) . . . . .	33
La medicalización de la transexualidad en niños y adolescentes. Aspectos éticos ( <i>Sabel Gabaldón Fraile</i> ) . . . . .	34
The ethical-psychological aspect of an interaction between transplant surgeons, donors, and society. "Congenital" defect of the development of transplantation [1] ( <i>Farida Maylenova Gabelhakovna</i> ) . . . . .	35
Environment in relation to health, wellbeing and human flourishing: The contribution of 20th century continental philosophy of life and of the subject ( <i>Marie Gaille</i> ) . . . . .	36

Balancing care and justice in disability ( <i>Lucia Galvagni</i> ) . . . . .	37
Global Health Emergencies, Gender and Vulnerability ( <i>Agomoni Ganguli-Mitra</i> ) . . . . .	37
Withholding and withdrawing treatment, a multicentre study in patients admitted in Internal Medicine wards in the Community of Madrid ( <i>Rebeca García Caballero, Diego Real de Asúa, Sergio Gámez, Gala Vega, Emanuele Valenti &amp; Benjamín Herreros Ruíz-Valdepeñas</i> ) . . . . .	38
Guía de actuación ante la pérdida perinatal en el Parc Sanitari Sant Joan de Deu ( <i>C. Garcia Terol, B. Carreras Marcos, R. Martin Rodrigo, E. Meleiro Trillo, I. Pérez Pinedo, P. Ricciardeli &amp; E. Reus Calvo</i> ) . . . . .	39
Ethics Experts: still wondering whether they do exist. How are they expected to help in clinical ethical decision-making? ( <i>Alessandra Gasparetto</i> ) . . . . .	40
What is an healing space for Disorders Of Consciouness ( <i>Charlotte Gilart de Keranflec'h</i> ) . . . . .	41
Uso de muestras biológicas y registros clínicos en la investigación. Límites del deber de respeto a la autonomía ( <i>María Inés Gómez, Lorna Luco &amp; Patricio Michaud</i> ) . . . . .	42
Problems of social justice in use of biomedical technologies for human enhancement ( <i>Elena Grebenshchikova &amp; Boris Yudin</i> ) . . . . .	43
Integrated clinical ethics consultation as an educational resource for medical professionals ( <i>Antonia Grigorova &amp; Silviya Aleksandrova-Yankulovska</i> ) . . . . .	44
Emerging Integrative Ethics Support: Experiences with providing continuing ethics support for a treatment team that provides care for transgender persons ( <i>L. A. Hartman &amp; Albert Christiaan Molewijk</i> ) . . . . .	45
Future of the freedom to provide crossborder health care services ( <i>Hana Horak &amp; Nada Bodiroga Vukobrat</i> ) . . . . .	46
“Why Should I Question a Patient’s Wish?” A Comparative Study on Physicians’ Perspectives on Their Duties to Respect Advance Directives ( <i>Ruth Horn</i> ) . . . . .	46
Proposta d’un nou fonament de la vulnerabilitat ( <i>Marc Illa Mestre</i> ) . . . . .	47
“Growth itself is the only moral end” . The relevance of Dewey’s moral theory for continuous ethics education of healthcare professionals ( <i>Giulia Inguaggiato, Suzanne Metselaar, Rouwen Porz &amp; Guy Widdershoven</i> ) . . . . .	48
To Fix or Not to Fix, the Cosmetic Labiaplasty Question ( <i>Eghoihunu Ireo</i> ) . . . . .	49
The assessment of capacity: Challenges faced by Swiss Clinicians ( <i>Luzia Iseli, Helena Hermann, Manuel Trachsel, Tenzin Wangmo &amp; Bernice S. Elger</i> ) . . . . .	49
Which outcomes of Moral Case Deliberation do participants perceive as important and which do they experience? – Insights from the field study with the Euro-MCD Instrument ( <i>J. C. de Snoo-Trimp, M. Svantesson-Sandberg, Albert Christiaan Molewijk, H. C. W. de Vet, Guy Widdershoven, B. S. Brinchmann &amp; G. Ursin</i> ) . . . . .	50
CRISPR/CAS9: Patent war for controlling the book of life in the era of Bioprecariousness ( <i>Sonia Jimeno</i> ) . . . . .	52

Factors that challenge and facilitate research integrity: a qualitative study of researchers and advisors in the UK ( <i>Mari-Rose Kennedy &amp; Ruud ter Meulen</i> ) . . . . .	53
Healthcare professionalism at times of austerity ( <i>Angeliki Kerasidou &amp; Patricia Kingori</i> ) . . . . .	54
The mother of invention – how policy makers use necessity argumentations in health care coverage decision practice ( <i>Tineke Kleinhout-Vliek, Antoinette de Bont &amp; Bert Boer</i> ) . . . . .	54
Care and Justice in the Hospital Arena ( <i>H. Kohlen &amp; A. A. M. van Nistelrooij</i> ) . . . . .	55
Has moral case deliberation impact on the degree of moral sensitivity on employees in (forensic) psychiatric care? ( <i>Swanny Kremer, Duco Kroon, Albert Christiaan Molewijk &amp; Marinus Spreen</i> ) . . . . .	56
A developing country’s socioeconomic perspective of informed consent in clinical practice ( <i>Brenda Kubheka</i> ) . . . . .	57
Neurodegenerative diseases and global and/or specialized care : practices and discourses ( <i>Mathilde Lancelot &amp; Agathe Camus</i> ) . . . . .	57
Sharing Care Responsibilities between Professionals and Families in Mental Healthcare. A Plea for Inclusion ( <i>Elleke Landeweer</i> ) . . . . .	58
Enjeux pédagogiques de la culture palliative: quel apprentissage social de l’accompagnement de la fin de vie? ( <i>Rozenn Le Berre &amp; Grégory Aiguier</i> ) . . . . .	59
Réflexion éthique et soins palliatifs : la perspective des éthiques du care ( <i>Rozenn Le Berre</i> ) . . . . .	60
Between palliative care and euthanasia: doing justice to the most vulnerable ( <i>Carlo Leget</i> ) . . . . .	61
Influence of an ACP intervention on documentation of end-of-life issues – a cluster randomized clinical trial ( <i>Trygve Johannes Lereim Sævareid, Lisbeth Thoresen, Reidun Førde &amp; Lillian Lillemoen</i> ) . . . . .	62
Implementing advance care planning (ACP) in Norwegian nursing homes; a process of knowledge translation. ( <i>Lillian Lillemoen</i> ) . . . . .	63
Mejorando el acceso al tratamiento anticoagulante como parámetro de justicia en la atención de pacientes con enfermedad cardiovascular ( <i>Lorna Luco , María Inés Gómez &amp; Carmen Astete</i> ) . . . . .	64
Beyond gift-giving: transplantations, agent identity, and sharing ( <i>Pawel Luków</i> ) . . . . .	65
La qualité de la vie, qu’est ce que cela signifie aujourd’hui ? / Quality of Life: what does it mean today ? ( <i>Milena Maglio</i> ) . . . . .	66
Justice and Vulnerability in Childcare ( <i>Júlia Martín Badia</i> ) . . . . .	66
Goodness Versus Fairness in Public Health Decision Making: Designing an Animated Bioethics Learning Module ( <i>Hannah McLane &amp; Nate Totushek</i> ) . . . . .	67
Determinants of New and Emerging Labour Risks in the Workplace : Health and Safety Practice in Spain ( <i>Teodor Mellen &amp; Helena Roig</i> ) .	68

The Intersection of Hospice Care and Family Dynamics: What happens when End of Life Care and Child Care Collide? ( <i>Maximiliano Mendieta</i> ) . . . . .	69
The use of Restraint in dementia patients: can we include it in a care project? ( <i>Elena Montaguti &amp; Federico Nicoli</i> ) . . . . .	70
Implicaciones éticas de la telemedicina en el control remoto de dispositivos cardíacos implantables ( <i>María José Ruiz Montilla, Joan Costa Mateu, María Tornel Cerezo &amp; Anna Baiget Pons</i> ) . . . . .	71
The limit of doctor professionalism to support patient decision making ( <i>Akira Nakazawa</i> ) . . . . .	72
Necessity of Scientific Tribunals: Scientific Regulation of Medicine in Context of Philosophy ( <i>Eva Neu, Michael Ch. Michailov, Christoph Lütge, Tatjana Senn, Ursula Welscher, Ralf K. Stappen, Albert Oswald, Heike Wankel, Michael Schratz, Rumen Stainov &amp; Germain Weber</i> ) . . . . .	73
Clinical Ethics Consultation Service: an overview after one year of activity ( <i>Federico Nicoli, Jean Pierre Ramponi &amp; Mario Picozzi</i> ) . . . . .	74
“We Will Stop Femicide”, A Platform Fighting against Gender-Based Violence ( <i>Gulsum Onal &amp; Yesim Isil Ulman</i> ) . . . . .	75
La cesárea a demanda: Un conflicto de valores y un dilema a resolver ( <i>Gabriel Orce</i> ) . . . . .	77
Place of bioethics in continuing education for nurses in Kharkiv National Medical University ( <i>Tetyana Ospanova, Iryna Sorokina &amp; Mykhailo Myroshnychenko</i> ) . . . . .	78
Quality of life in patients with chronic diseases ( <i>Tetyana Ospanova, V. Lesovoy1, N. Zaozerskaya, A. Chernykova, Iryna Sorokina &amp; Mykhailo Myroshnychenko</i> ) . . . . .	79
Fundamentación ética de las estrategias para la seguridad de los pacientes ( <i>Rosa M<sup>a</sup> Pérez Capellades</i> ) . . . . .	80
Informed Consent and the Royal College of Surgeons’ Guide to Good Practice – Are Patients Giving Fully Informed Consent? ( <i>Ary Phaily, Chudy Uzoho, John Thomas &amp; Sanjiv Manjure</i> ) . . . . .	81
Stigma and mental illness in mass media ( <i>Josep Pifarré, Jesús Cornejo &amp; Montserrat Esquerda</i> ) . . . . .	82
Which core skills for Healthcare Ethics Consultations in Disaster Medicine? ( <i>Istvan Piffer Gamberoni, Federico Nicoli &amp; Mario Picozzi</i> ) . . . . .	82
Truth-telling to a cancer patient about poor prognosis: a clinical case report in cross-cultural communication ( <i>Mohammad Razai</i> ) . . . . .	83
Value of Life - Intrinsic or Personal? ( <i>Angelika Reichstein</i> ) . . . . .	84
A question of fairness: Shall cost be a criterion to withhold opioid-assisted therapy from elderly, incapacitated patients? ( <i>Stella Reiter-Theil, Jan Schuermann, Kenneth Duersteler &amp; Marc Vogel</i> ) . . . . .	84
Broad consent for healthcare-embedded biobanking: understanding and reasons to donate in a large patient sample ( <i>Gesine Richter, Michael Krawczak, Wolfgang Lieb, Lena Wolff, Stefan Schreiber &amp; Alena Buyx</i> ) . . . . .	85
A matter of justice: moving from values to conduct ( <i>Laia Riera Armengol &amp; Gemma Torrell</i> ) . . . . .	87

An ethical dilemma in communicating genetic information in families: respect for autonomy and privacy in conflict with beneficence and non-maleficence. ( <i>Adelheid Rigo &amp; Johan Stuy</i> ) . . . . .	88
End-of-life decisions and people with disabilities: disability rights or care ethics subject? ( <i>Daniela Ritzenthaler</i> ) . . . . .	89
Gender and dementia bias. Can biology explain everything? ( <i>B. Robles, P. Valls, M. Tramunt, D. Muñoz, J. Graells &amp; N. Parellada</i> ) . . . . .	90
Burden of treatment in face of childhood cancer: A quantitative study based on medical records of deceased children ( <i>Michael Rost, Tenzin Wangmo, Milenko Rakic, Elaine Acheson &amp; Bernice Elger</i> ) . . . . .	91
Cutting to the core domains of pediatric palliative care: A critical analysis on international guidelines ( <i>Michael Rost, Eva de Clercq, Tenzin Wangmo &amp; Bernice Elger</i> ) . . . . .	92
Sustainability of national health services and justice: the case of new DAAs for HCV in Italy ( <i>D. Sacchini, P. Refolo, R. Minacori, L. Craxì &amp; A. G. Spagnolo</i> ) . . . . .	93
Clinical ethics consultation as “shared document”. Emerging ethical and medico-legal issues: the experience of IBioMedH-UCSC CEC Service (2005-2016) ( <i>D. Sacchini, B. Corsano, P. Refolo, R. Minacori &amp; A. G. Spagnolo</i> ) . . . . .	94
The dual use of research ethics committees. Why professional self-governance falls short in maintaining the balance between academic freedom and biosecurity ( <i>Sabine Salloch</i> ) . . . . .	95
Ethical Expertise in Ethics Consultation: An empirical-ethical analysis of concepts and implications for evaluation research ( <i>Jan Schildmann, Joschka Haltaufderheide, Stephan Nadolny &amp; Jochen Vollmann</i> ) . . . . .	96
End-of-Life-Care: Making Ethics Consultation Visible ( <i>Kurt W. Schmidt</i> )	97
Opportunities and risks of supported decision-making in dementia research: An ethical analysis ( <i>Matthé Scholten, Jakov Gather &amp; Jochen Vollmann</i> ) . . . . .	98
“I think that a country, a society is worth only as much as it treats their weakest.” – Subjective views on health, illness and the provision of care of three involved parties in home nursing. ( <i>Anna-Henrikje Seidlein, Ines Buchholz, Maresa Buchholz &amp; Sabine Salloch</i> ) . . . . .	98
Getting Clearer about Big Data and its Ethical Issues ( <i>Mark Sheehan</i> ) . . . . .	100
Evidence or bumbledom: nootropics between scientific values and public request ( <i>Sergey Shevchenko</i> ) . . . . .	100
Geriatric long-term facilities : uses and misuses of justice ( <i>Marta Spranzi</i> )	101
The effectiveness of computer-based learning (CBL) and classroom lecture as teaching method of bioethics in medical school: A comparison study ( <i>Yoyo Suhoyo, Ova Emilia &amp; Tridjoko Hadiananto</i> ) . . . . .	102
Values in conflict during the decision making process surrounding admission to intensive care – Ethnographic study in six British hospitals ( <i>Mia Svantesson-Sandberg, Frances Griffiths, Chris Bassford &amp; Anne Slowther on behalf of the ICU-decision making study team</i> ) . . . . .	103

Work, health and disability: capability and a physician's perspective ( <i>Jacques Tamin</i> ) . . . . .	104
HIV Written Informed Consent: Time to Review the Italian Standard? ( <i>Jacopo Testa, Alessandra Gasparetto, Elena Montaguti, Federico Nicoli &amp; Mario Picozzi</i> ) . . . . .	105
Social Responsibility and Health from Six Religious Perspectives ( <i>Joseph Tham</i> ) . . . . .	106
On Double Helix of Life Technologization: Co-production of Knowledge, Technologies and Values ( <i>Pavel Tishchenko &amp; Olga Popova</i> ) . . . . .	107
El paper dels coordinadors d'Equips d'Atenció Primària: conflicte de lleialtat? ( <i>Gemma Torrell Vallespín</i> ) . . . . .	108
Demencia severa: hacia un enfoque terapéutico justo. ( <i>Ainhoa Unzurrunzaga Diaz, Esther Martinez Becerro &amp; Raquel Jaso Tejera</i> ) . . . . .	109
Impacte del Programa Comunitari al SRC Granollers Benito Menni en la integració social dels usuaris ( <i>Mònica Alonso Valcárcel, Olga Ayza Pérez, Marc Garcés Domingo, Ignasi Garcia Naranjo, Belén Gías Gil, Queralt Torres Cayuelas &amp; Lourdes Tudela Cantallops</i> ) . . . . .	110
Dealing with a request for assisted suicide in psychiatry: a training module for psychiatrists in the Netherlands. ( <i>Laura van Melle, Eric Ettema, Yolande Voskes, Albert Christiaan Molewijk &amp; Guy Widdershoven</i> ) . . . . .	111
Institutional space for multi-perspective decision-making: what are the challenges? ( <i>I. van Nistelrooij &amp; H. Kohlen</i> ) . . . . .	112
Nanomedicine and human health: when big questions arise from small technologies. ( <i>Vittoria Viganò &amp; Mario Picozzi</i> ) . . . . .	113
Why cannot Western individualism be comprehensive? Vaccine refusal debates in Turkey ( <i>Mustafa Volkan Kavas</i> ) . . . . .	114
Autonomy and coercion in psychiatry, a care ethics perspective ( <i>Yolande Voskes &amp; Guy Widdershoven</i> ) . . . . .	115
The role of scientific experts and their perceived responsibility towards society. A qualitative interview study with natural scientists ( <i>S. Wäscher, A. Deplazes Zemp &amp; N. Biller</i> ) . . . . .	116
Which health inequalities are unjust? Moving the dialogue between theory and practice forward ( <i>Verina Wild</i> ) . . . . .	117
"It is lonely at the top" – exploring ethical challenges of head physicians ( <i>Benjamin Willi, Caroline Brall &amp; Rouven Porz</i> ) . . . . .	118
Promote empathy, not only as an improvement for professional burnout, but a key element in the quality of care ( <i>Oriol Yuguero, Montserrat Esquerda, Joan Viñas, Josep Pifarré &amp; Jorge Soler</i> ) . . . . .	118
Honest intellectual leadership of a scientist in research within the higher education: being ethical, moral and responsible ( <i>Vilma Zydziunaite &amp; Aivaras Anuzis</i> ) . . . . .	119
Retaining for scientist's reputation within the ethical intellectual leadership in higher education through being open and seeking for quality, and meaningfulness in research ( <i>Vilma Zydziunaite &amp; Aivaras Anuzis</i> ) . . . . .	120

Co-payments for unfunded additional care in publicly funded healthcare systems: ethical issues ( <i>Joakim Färdow, Linus Broström &amp; Mats Johansson</i> ) . . . . .	123
Ethical Considerations in the Assessment of Risks in Social, Behavioral and Educational Research and the Role of the Ethics Committee or Institutional Review Board ( <i>Colleen M. Gallagher</i> ) . . . . .	123
4 years experience of Medicine and Literature Lecture Elective Course in Marmara University Faculty of Medicine ( <i>Sefik Gorkey &amp; Orcun Cil</i> )	124
Ensuring the safety of participants of clinical trials ( <i>A. Khokhlov &amp; N. Chudova,</i> ) . . . . .	124
On Socio-Psycho-Somatics in Medical and Juridical Philosophy ( <i>Michael Ch. Michailov, Eva Neu, Peter Birkenbihl, Guntram &amp; Edith Schulz , Iva &amp; Sonya Ivanova, Michael Traub, Ursula Welscher, Janka &amp; Viktor Foltin , Manfred Holler , Christoph Lütge , Michael Schratz , Germain Weber</i> ) . . . . .	125
Fragmented food autonomy: the meat industry as a social determinant of health and counter-capability factor ( <i>Cristian Moyano Fernández</i> ) . .	127
Exploring the ethical issues of growth hormone treatment for idiopathic short children as a case of medicalisation ( <i>Maria Cristina Murano</i> ) .	128
Utilitarianism and Egalitarianism in Organ Allocation ( <i>Piotr Grzegorz Nowak</i> ) . . . . .	128
The “time of waiting”: the Nurse and the end-of-life choices in the Neonatal Intensive Care Unit ( <i>Renzo Pegoraro</i> ) . . . . .	129
Nuevo abordaje del control de la Hidradenitis Supurativa (HS), enfermedad crónica de gran repercusión psicológica y socio-laboral desde una Unidad Multidisciplinar y la Voz de los pacientes: Reflexión Ética sobre el “Barómetro social” de esta enfermedad ( <i>Cristina Pelufo &amp; Antonio Martorell</i> ) . . . . .	130
Mejora de la Calidad Docente en Cuidados Paliativos ( <i>Emanuele Valenti, Tayra Velasco, Benjamín Herreros Ruíz-Valdepeñas , Beatriz Moreno, Cristina Coca &amp; Eduardo Pacios</i> ) . . . . .	132

**Author Index**

# Keynote sessions

## The normative significance of social determinants of health

Thomas Schramme  
University of Liverpool

In this paper I critically discuss the normative significance of so-called social determinants of health and their use in public health policy. I will highlight certain possible and real misperceptions that are common in public health research and public health policy. After introducing the concept of the social determinants of health, the first issue I discuss concerns the confusion surrounding the notion of health in public health. Public health is mainly concerned with health dispositions or risks. This is different from a concern for people being unhealthy in the sense of suffering from a disease. The difference is important for the notion of health inequalities as well. In order to deem some people less healthy than others, a gradual concept of health is needed. Once the two concepts of health are confused, it is more difficult to acknowledge normative differences between being unhealthy and being less healthy. I submit that public health policies tend to exploit the common attitude towards diseases, namely that they ought to be treated and that they establish claims of justice. It is then another step of public health practitioners to campaign against social conditions that lead to certain health inequalities, which are deemed unjust. In other words, public health allows a normative argument, via the value of health, against specific social conditions. I reject this approach and allow only an indirect role for inequalities of health dispositions in an account of social justice. They might be regarded as symptoms of social ills, but they are not, according to my mind, as such unjust. Injustice in social conditions needs to be established in its own right, not mainly via their impact on health dispositions in specific populations. In the final section I hint towards an alternative, a noncomparative theory of social justice, which aims at enabling citizens to make healthy choices, but is not *per se* interested in comparative differences between people.

---

## Health Care Systems – At the Service of What?

Yvonne Denier  
University of Leuven

“We provide three kinds of services – cheap, quick, and reliable. You can have any two, but you cannot have all three. If it’s cheap and quick, it won’t be reliable. If it’s cheap and reliable, it won’t be quick. And if it’s quick and reliable, it won’t be cheap.” (Butler, 1999)

What does just health care imply? Does it mean that people have a right to health care? Does it entail that there are rights-based social obligations to provide equal access to health care for everyone? And if so, why? Why are health care interests so important that they deserve special protection? What kind of social good is health care? What is its essential goal? What are its functions and do these make it different from other commodities that we can buy on the market?

Furthermore, how much equality should there be in health care? And which kinds of equality are we talking about – Equal health? Equal use of health care? Equal access? Equal choice sets?... What inequalities are morally acceptable and how should the burdens of achieving equality be distributed? Which matters of health care belong to the domain of justice, and which to the domain of charity? To what extent should we allow personal responsibility to play a role in allocating health care services and resources, or in distributing the costs? And what does justice require with regard to long-term care for the chronically ill and irreversibly dependent?

Since the 1990’s, issues of scarcity, priority setting, and rationing lie at the centre of most current debates on health care. These are pressing issues: one way or another, limits have to be set. As such, the question of what is involved in just health care becomes much more complex. This complexity can be represented as an inconsistent triad, a set of three propositions of which any two are compatible but which together form a contradiction. In the case of health care, the three rival values are: economic efficiency, social justice, and comprehensive decent-quality care. It seems to be that we can have any two but not all three.

Essentially, the central question is the following: how best to square the proverbial welfare circle. How can resources be matched to needs, or needs to resources in socially acceptable and economically feasible ways?

In my lecture, I will attempt to answer the question “How can health care be incorporated into a comprehensive theory of justice, while realizing an acceptable balance between efficiency, justice and care?”

---

# Justice and vulnerability

Begoña Román-Maestre

University of Barcelona

Three are the aims of this keynote:

1. Vulnerability characterizes human being and it is in the basis of Ethics. Justice is the answer for the vulnerability.
2. Bioethics has promoted autonomy in order to overcome all kind of dependence. This conception of autonomy derives of the modern philosophy and the liberal anthropology. Contemporary philosophy has been critical with this modern individualism and with this isolated autonomy.
3. Bioethics should be opened to the new approaches that reconsidered vulnerability can offer. Solidarity and fraternity are more than topics of good intention people: they point at the political structures and can become criteria for the assessment of the health systems.

The speech is divided in three sections.

1. Justice and vulnerability: about the words and its meanings
  - (a) Justice
    - Justice as human treat: dignity, respect and rights
    - Justice as participation: dialogue and consent
    - Justice as distribution: goods and risks
  - (b) Vulnerability
    - Human condition: autonomy is always a grade with respect vulnerability
    - Corporal, Mental, Social and Moral Vulnerability
    - The lack of recognition: social sources of the self
2. Social Determinants of Health: a matter of justice
  - Poverty, legal citizenship, gender violence, low level of education are factors that imply more likelihood of falling ill.
  - To be victim or to be autonomous
  - The fallacy of contractarianism: “volenti non fit inuria”? (Pogge)
  - A universal vulnerability: the misperceptions of safety in the society of risk. Living with fear
3. Normative solidarity and political fraternity
  - The deference to the difference: the fight against the bad luck of the social determinants of Health.
  - We are neither in the original position (Rawls) nor in the ideal community of dialog (Habermas), nevertheless both of them are good criteria of justice.

- Fraternity is political: a common Humanity. Capabilities and global justice: a matter of institutions, of democracy but too of creativity: index for human development (Nussbaum and Sen).
- Emotional and rational solidarity; motivations and foundation: both aspects are needed. Indifference is a form of complicity: more for everybody means necessarily less for a few. That's the hard question of prioritizing in health.

---

## **Round table. Quaternary Prevention(P4) or first do not harm**

Marc Jamoulle<sup>1</sup>, Patrick Ouvrard<sup>2</sup>, Daniel Widmer<sup>3</sup>, Ricardo La Valle<sup>4</sup> & Miguel Pizzanelli<sup>5</sup>

<sup>1</sup>Department of general Practice, Liège University. Belgium; <sup>2</sup>Société de formation thérapeutique du généraliste, France; <sup>3</sup>Institut Universitaire de Médecine Générale, Lausanne, Switzerland; <sup>4</sup>Quaternary Prevention Commission of the Argentinian Federation of Family and General Medicine & WONCA Special interest group in Quaternary Prevention and Overmedicalisation (P4&O SIG); <sup>5</sup>Department of Family and Community Medicine, UdelaR, Montevideo, Uruguay & WONCA Special interest group in Quaternary Prevention and Overmedicalisation (P4&O SIG)

Quaternary prevention (P4), born from a reflection on the doctor-patient relationship, began as an answer of family doctors facing overmedicalization. It aims to protect the patient or population against the danger of medicine. Harmful effects can appear with preventive activities (example: prostate cancer screening by PSA) as well as by therapeutic interventions (example: disruptive medicine). P4 promoted by the World Organization of Family Doctors (WONCA) is practiced in different ways around the world through the activity of the WONCA Special Interest Group on Quaternary Prevention and Overmedicalisation (P4&O).

There are multiple initiatives and backgrounds of P4. All these multiple initiatives that lead to P4 have their origin in denouncing the inadequacies of the Hegemonic Medical Model and the excesses perpetrated in the pursuit of profit. There are many schools of thought that try to solve this situation, such as “Medicines Based on...” These contributions are valuable but usually point to a single dimension of the problem so they do not change the situation too much. The P4, however, have understood the centrality of the political and economic dimensions and, that is why, P4 has become a movement.

P4 has understood that the root causes far exceed the limits of medicine, have understood that the problem includes ethical, political, economic and epistemological aspects of medicine. It is for this reason that the definition of P4 has shifted to the function of foundational idea since the movement that has been generated around this concept has surpassed this initial definition centered in a, yet complex, but still medical vision. P4 has understood that a new model of medicine and a new pact with society is necessary.

P4 is a counter-hegemonic movement with predominant development in peripheral countries. This movement includes many other perspectives developed in the

central countries but is the only one that has an ideological position that discusses the current paradigm of medicine that legitimates the same causes that give rise to P4, proposing to think a new way of practice the medicine that includes Ethical values, other forms of knowledge and the return to human medicine for humans with place for uncertainty, compassion, the encounter between people and non-commodified.

Justice in health care is a central aspect of this new way of conceiving the medicine that we propose. Remember what Rudolf Virchow said in the nineteenth century “*Physicians are the natural advocates of the poor and social problems fall largely under their jurisdiction. Medicine is a social science, and politics is nothing more than medicine in large scale*”. We must reformulate our contract with society and for this we must be very clear that our loyalty must always be with the sick, the poor and those who are weak. For this new contract we must also take into account the magnitude of the power that has been given to us and to live up to such responsibility.

In the Rio manifesto (2016) we propose to “Avoid and denounce the naturalization of: hunger, exclusion, manipulation, inequality, violence, racism, exploitation, which harm health more than ‘diseases’”. There is a better and fairer world, let’s fight to get it!

More about P4 on [www.ph3c.org/p4](http://www.ph3c.org/p4)

References:

- French: Widmer D, Herzig L, Jamouille M. Prévention quaternaire : agir est-il toujours justifié en médecine de famille ? *Rev Med Suisse* 2014; (10):1052-6. <http://www.ncbi.nlm.nih.gov/pubmed/?term=24930150>
- English: Jamouille M. Quaternary prevention, an answer of family doctors to overmedicalization. *Int J Heal policy Manag* [Internet]. 2015 Feb;4(2):61–4. <http://www.ncbi.nlm.nih.gov/pubmed/25674569>
- Portuguese: Silva AL da, Mangin D, Pizzanelli M, Jamouille M, Wagner HL, Silva DHS, et al. Manifesto de Curitiba: pela Prevenção Quaternária e por uma Medicina sem conflitos de interesse. *Revista Brasileira de Medicina de Família e Comunidade*. 2014. p. 371–4. <http://www.rbmf.org.br/rbmfc/article/view/1006>
- Spanish: Nève J, Bernstein J, Terra MA. Prevención cuaternaria, una tarea explícita del médico generalista . Una entrevista con Marc Jamouille. *Arch Med Fam y Gen*. 2013;10(2):23–6. <http://archivos.famfyg.org/revista/index.php/amfyg/article/view/130/116>; La Valle R. Prevención cuaternaria o medicina sin corbata. *Archivos de Medicina Familiar y General* 2015;12(2):5-6. (2015-07) - 2015, v.12, p.5-6. URL: <http://archivos.famfyg.org/revista/index.php/amfyg/article/viewFile/198/157>; Menéndez E. El modelo médico y la salud de los trabajadores. *Salud Colectiva*. 2005;1(1):9-32.; Bernstein J. La Valle R. Piñero A., Jacob G. P4, presente y futuro. Manifiesto de Rio. Disponible en: <http://www.nogracias.eu/2016/12/26/la-salud-como-resistencia-un-manifiesto-por-la-prevencion-cuaternaria/>



# Oral Communications

## Relationship between science and ethics in Argentina: science with consciousness

Session 4  
Room 5

Silvina Ávila<sup>1</sup>, Paula Sánchez Thevenet<sup>2</sup>, Pasqual Gregori Roig<sup>3</sup>, Monica Souto<sup>1</sup>,  
Cristian Silva<sup>1</sup> & Andrea Maza<sup>1</sup>

<sup>1</sup>National University of the Patagonia San Juan Bosco, Chubut, Argentina; <sup>2</sup>Department of Medicine, Faculty of Health Science, Universidad CEU Cardenal Herrera/ CEU Cardenal Herrera University, Castellón, Spain; <sup>3</sup>Clinical Research Ethics Committee, University Hospital of La Plana, Villarreal, Spain.

Science has its own method of study and it is necessary for human progress. In Argentina, after a first stage of establishing Bioethics in healthcare, it has been proven that it is necessary to endorse the value dimension in research. In a prior study carried out about the period 1988-2008, we showed that the ethical requirements for research publishing was a matter that needed improvement, we also saw that there was a larger contribution from Argentinian authors into clinical ethics and we identified bioethical elements in some regulations on research (*Acta Bioethica* 2011; 17 (1): 105-114). It was concluded that the relationship between science and ethics was under construction and that, in some scientific forums, the paradigm of science exempt from ethical judgement (scientific neutrality) was still predominant.

The objective of this study is to bring up to 2016 the situation of the science-ethics relationship, at national and regional level (Patagonia). A mixed design (quantity/quality) was used, especially focused on the zoonosis research model as zoonosis are diseases shared by humans and animals. Observable public products were analyzed: from national and regional regulations, guidelines from scientific journals, ethical committees in research and scientific ethics organizations, national references documents, press articles about science and training on research ethics.

The findings showed that the ethical dimension goes through the legal instruments in terms of studies on life sciences. In that sense, a milestone was reached when, thanks to the Resolution 1480/2011 of the Ministry of Health, the ReNIS (National Register of Health Research) and the Guidelines for Research with Human Beings were created. Moreover, for zoonosis research, the principles included in international guidelines on research ethics must be guaranteed, whose regulation is possible thanks to many national and regional rules. In a short while, the scientific community has taken qualitative steps in order to overcome the tension between legality and legitimacy. Also the training on ethical research with human beings, on/with animals and on the environment has increased in the country.

The requirements for ethical justification and scientific validity for the publication of studies in national journals have been optimized. But the press still needs to improve their dealing with scientific matters. In conclusion, the relationship between science and ethics in Argentina has overcome the paradigm of scientific neutrality and it is entering a period of consolidation. This means that the vulnerability of the subject of the investigation has diminished and that the limit of science, purely methodological, based on scientific rigor, has been overcome, allowing a transition to a phase of more useful social knowledge.

---

Session 3  
Room 3

## **Pediatric palliative care decision making in Switzerland**

Elaine Acheson, Michael Rost, Nadia Pacurari, Bernice S. Elger & Tenzin Wangmo  
University of Basel

**Introduction.** The importance of pediatric palliative care (PPC) is highlighted by the International Society of Pediatric Oncology and the American Academy of Pediatrics. They advocate an integrated model of palliative care for all children with life-threatening diseases that should begin at diagnosis and continue throughout the course of illness regardless of the outcome. In addition, very little is known about how children and adolescents are involved in decision-making concerning PPC. The purpose of this study is to examine whether children who died from cancer received PPC, and if so, when did PPC begin as well as how the DM process took place during their illness period.

**Method.** Seven Swiss Pediatric Oncology Centers participated in this study. Using a standardized data extraction form, a retrospective review of medical records of deceased pediatric patients took place. In this study, information on 193 cases were included and the variables studied were the following: diagnosis, treatments, palliative care, and decision-making in the course of transition to palliative care. All extracted data were entered into SPSS.22 and first descriptively analysed. Thereafter, we performed analysis of variance and Chi-square test of independence to assess differences concerning PPC using three diagnosis groups.

**Results.** The average age of the sample at diagnosis was 7.2 years and the average age at which the sample received PPC was 9.5 years. Almost two-third of the sample suffered from CNS neoplasms and Leukemias. Information on when PPC began was recorded for 170 cases, of which 38 did not receive palliative care. Of the remaining 132 cases, in only 16 cases palliative care started at diagnosis. The mean duration of palliative care was 145 days (Mdn = 89.5, SD = 183.4, range: 2 - 1111 days). Decision to begin palliative care was discussed solely with parent(s) in 60.9% of the cases (70 out of 115), with parent(s) and the child in 34.8% of the cases (40 out of 115), and first with the parents and afterwards with the child in 4.3% of the cases (5 out of 115). Those children who were included in the palliative care decision-making were 13.6 years of age (SD = 4.6), whereas children that were not included were 7.16 years of age (SD = 3.9). Finally, leukemia patients were less likely to receive palliative care than the overall sample.

**Discussion.** Our findings suggest that the recommendation of PPC being implemented from cancer diagnosis onwards is not yet followed in Switzerland and this

could be due to cultural as well center specific values towards ensuring hope to the family and doing all that is possible until the very end. Medical staff members need continued education and intensive training if inclusion of PPC as recommended by pediatric associations is to become a standard practice.

---

## **Ethics of deemed consent: The new Welsh approach to organ procurement and the role of the family**

Andreas Brøgger Albertsen  
Aarhus University, Denmark

Session 4  
Room 1

In Wales ‘The Human Transplantation Act’ came into force on December first, 2015. This new legislation has broader relevance for the discussion of procurement and ethics. The law changed the Welsh procurement of organs for transplants. Wales became the first part of the UK to move away from an opt-in system in the procurement of organs. The new system has been termed deemed consent. Under the new law, people who have lived in Wales for more than 12 months, and who do not opt in to the organ register or opt out, will be regarded as having consented to organ donation, if they die. We must conduct a conceptual and legal analysis. In which way does deem consent differ from other opt-out legislation, where consent is presumed if people do not opt-out from the donor register.

The paper compares the laws with existing opt-out systems (or, tacit consent systems) and thus provides conceptual clarity as to whether the Welsh law is different from existing opt-out systems. This conceptual analysis shows that the Welsh system is very similar to what the literature calls a soft opt-out system. A system, where people are donors by default, but where transplantation is not performed if the family objects.

We must also evaluate the effectiveness of the new legal framework. To do so, the paper looks into data from the NHS Blood and Transplantation register, to give a preliminary assessment. Hopefully this will enable us to have a fuller understanding of the influence the new legal framework has had on procurement rates. During 2016, a total of 160 organs were transplanted, with 39 coming from people whose consent, was deemed through the new legal framework.

Interestingly, the system also shows a drop in the family refusal rate. The ethical aspects of the deemed consent proposal must also be evaluated. In the end the new legislation is discussed from one specific perspective, that of the family. UK has one of the highest family refusal rates in Europe, with families blocking a large proportion of would be donors from donating. With this knowledge in mind, the paper evaluates the role of the family in the Welsh law. As the family is still assigned a prominent role under the new law, the paper discusses the relative merits of the family’s right to refusal under the new Welsh law and under the practices existing in the rest of the UK. In the end, the paper argues that while the role of the family in Wales may be less problematic, it is still a cause for concern from an ethical perspective.

---

## Ethical aspects of preventive activities in general practice in Bulgaria

Silviya Aleksandrova-Yankulovska & Toni Vekov  
Medical University-Pleven

Focus on preventive activities and strengthening of primary health care have been amongst the priorities of strategies of WHO and health policies on national level. Targeting risk factors primary prevention aims at limiting the incidence of disease while secondary prevention aims to reduce the more serious consequences of already existing disease. Immunization against the major infectious diseases and control of local endemic diseases are basic elements of primary health services.

The aim of this report is to present the organisation and to analyse the ethical aspects of prophylactic vaccinations and of services for diabetic patients as examples of primary and secondary prevention activities in general practice in Bulgaria.

Methodology. Content analysis of existing normative documents regulating general practice in Bulgaria with a special focus on immunizations and services for diabetic patients. Ethical reflection through application of principlism, utilitarianism and patients' rights.

Results and discussion. Last 5 years the immunization coverage with obligatory vaccinations in Bulgaria dropped off by 2 to 5% for the different vaccinations. Different barriers to realization of immunization programmes have been discussed, such as barriers related to the health system, health professionals, knowledge, and individual patient's beliefs. Respect for autonomy versus beneficence present the main conflict of principles in application of measures to guarantee compliance with the obligatory scheme of vaccination. Utilitarianism strongly supports it on the level of public health.

In the case of early detection and monitoring of diabetic patients Bulgarian health insurance system splits responsibilities between general practitioners and specialists. Limited times per visit and focus on medication violate the right of patients to information and endanger principles of health promotion. The importance of life style changes to prevent development of pre-diabetic to diabetic state has been proven. However, a recent small-scale study in Bulgarian primary practice reveals no or little time spent on health education of newly diagnosed diabetic patients. The experimental design confirmed the benefits of 30-minutes talk in the target group by 9% better glycemetic control, lower cholesterol levels and BMI. The simple and cost-effective approach, however, is not welcomed by general practitioners who seems to be overwhelmed with other activities, underpaid for preventive measures and in conflicting responsibilities with their colleagues-specialists. None of bioethics principles supports lack of health education which additionally violates the right to access to information, the right to highest attainable level of health and eventually the right to life.

Conclusion. New approaches to preventive measures should be applied in order to increase population compliance while respecting patients' rights. More health professionals can be involved in preventive activities in order to ease the overburden of physicians and to allow primary health services to fulfil their genuine tasks. The importance of proper monitoring of diabetic patients is undoubted in view of the

serious complications that burden not only the individual but the health care system. Currently the competences of nurses and midwives in health promotion and prevention in Bulgaria are not well utilized and their autonomous services for health education of diabetic patients should be granted.

---

## **Personnel's rights in provision of palliative care in Bulgaria**

Session 3  
Room 2

Silviya Aleksandrova-Yankulovska<sup>1</sup>, Nikolai Yordanov<sup>2</sup> & Maria Kostova<sup>2</sup>

<sup>1</sup>Medical University-Pleven; <sup>2</sup>Comprehensive oncological center-Vratsa)

Last decades palliative care in Bulgaria struggles not only to get proper attention of health politicians but also to attract more health professionals to practice in the field. For 20 years of existence Bulgarian hospices could not achieve recognition into the health insurance system and they still stay as private enterprises. Health insurance scheme is applicable only to a limited number of palliative care units which provide services for the most severe cancer cases. Lack of qualified personnel and its psychological and physical overburden are among the most often cited problems there.

The aim of this report is to discuss the issue of personnel's rights in provision of palliative care in Bulgaria through presentation and analysis of four cases from the palliative care unit in Vratsa, North Bulgaria.

Methods: Example cases are retrieved through the application of adapted METAP methodology for clinical ethics consultation applied in 32 cases in the Comprehensive oncological center in Vratsa. Specific instruments include: informational brochure, protocol of ethics meetings, information check-list, and feedback self-administered questionnaire. The methodology was presented to the head and the psychologist of the palliative care unit who organized ethical case discussions at place.

Results and discussion: A 68-years old patient and his wife behave rudely with the nurse and blame her of being unqualified because of swelling of patient's arm after intravenous manipulation. The nurse consider this to be patient's fault as a result of careless attitude to the intravenous device. Rude behaviour and obscene words toward another nurse are observed in the second case. The third case presents a 88-years old, disoriented and demented patient who throws bank of medicine towards the nurse and injures her. The last case is of a 66-years old patient who behaves aggressively and pretends to be served quicker regardless of the established procedure. In all of the cases ethics meetings were organized and the conflicts were mediated. However, at the first case the blamed nurse was not satisfied by the outcome. The cases can be related to several providers' rights in the European Convention on Human Rights and the European Social Charter: to work in decent conditions, to due process, to a fair hearing, to effective remedy, to protection of privacy and reputation, and to freedom of expression and information. The last case falls under the right to safe working conditions. The right of medical professionals to stand their ground is relevant to the first case.

Conclusion: Both interests of patients and health care providers are to be protected. Although excusable to some extent, the behaviour of the terminally ill patients in the above cases undermines professional reputation of health care providers.

The situations were mediated in behalf of the patients and continuing provision of care. Ethics meetings gave opportunity of all involved parties to express their viewpoints, which is a precondition for development of good therapeutic contact. One of the affected nurses, however, felt her rights endangered. It would be relevant to elaborate guidelines for similar cases in the future.

---

Session 2  
Room 3

## **Towards patient empowerment in Saudi Healthcare: The place of a Positive Patients' Rights Culture**

Faisal Almutairi, Ray Kirk & Pauline Barnett

Recently, the topic of patients' rights has become the focus of governments, international organizations, and health service providers. Patients have acquired a new role in the healthcare process and have become key players in health services. Since the beginning of this century, a number of governments have sought to legislate the rights of patients and force health care providers to pay more attention to patients' rights. This concern developed from its root in the human rights movement and gained impetus from the increasing number of cases of the infringement of patients' rights in healthcare settings. Despite the large number of studies that cover various aspects in the field of patients' rights worldwide, few examine the readiness of hospitals to implement patients' rights, in other words, their commitment to establishing a positive patients' rights culture.

In this paper, a mixed-methods approach was utilized to survey a simple random sample of 292 doctors, 550 nurses, and 334 hospitalized patients, using a self-administered question-naire. In addition, in-depth interviews with 9 managers and experts in the field of patients' rights were conducted. To analyse the results, a conceptual framework, the patients' rights' culture framework (PRCF), was developed, containing three levels: micro (health system), intermediate (community) and macro (healthcare providers, health professionals and patients). The aims of the study were first, to explore stakeholders' perceptions of the readiness and ability of public hospitals in Saudi Arabia to implement the Patients' Rights Charter, and secondly to identify the main factors that enable or hinder the implementation process. Success in answering these questions is expected to lead to help in building a positive patients' rights culture in public hospitals.

The findings of the study reveal that there are shortcomings in government hospitals and among health professionals, preventing them from providing a good environment for implementing patients' rights effectively. They indicate the importance of managerial factors in the success of the implementation process, in addition to factors dependent on health professionals and patients. Despite the willingness of patients and the readiness of health professionals to implement the Charter, there are various obstacles at management level that have led to failure in the implementation of the Patients' Rights Charter in hospitals. Contributing factors, such as publicising the Charter, clarifying the regulations, coordinating with other governmental and non-governmental organisations, creating an effective complaint system, providing advocacy services, and implementing an effective monitoring mechanism, were found to play an essential role enabling the implementation of patients' rights. A

very high level of commitment proved inadequate to protect patients' rights in the absence of these factors.

The findings suggest that health professionals and patients should be educated and involved in the planning and implementation stages. Their feedback and comments are vitally important sources that must be collected, evaluated and reviewed periodically. Finally, the study emphasises that creating a positive patient rights culture requires more serious and effective managerial commitment, as well as the activation of the role of community institutions in addition to the commitment of all stakeholders to their roles.

---

## **Top Four Ethical Issues in Romanian Healthcare System**

Session 2  
Room 3

Maria Aluas

Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania

Lately, mass media are very interested in physicians, patients and medical practices. Medical practices used for decades are denounced by patients, caregivers or healthcare professionals on social networks and media. Extreme cases are currently shown on television or on social networks. These cases generate fear in population concerning medical acts and the physicians' behavior. Patients fear being treated properly, family members/caregivers sue doctors in Courts and threaten, while physicians live and work under the rule of fear, doubt and confusion. It seems that everyone has something against all others.

This presentation is the result of three focus groups and interviews concerning these issues in everyday medical practice. Young physicians specialized in cardiology, oncology and radiology have participated to focus groups and interviews, and were asked about the main ethical issues of the healthcare system, their causes and generating factors, and to design possible solutions to eliminate or diminish conflicts and to avoid ethical issues. The conclusion is that they propose the following improvements: eliminate the corruption acts, more transparency, legal regulations and guidelines. These changes need to be a high priority in order that they can work properly. Also, it will be underlined Romanian cultural particularities.

---

## **“Striking a Balance”: Could a mandatory medical practitioner reporting scheme of intimate partner violence be legally and ethically justified**

Raj Amarnani

University of Sheffield

Intimate partner violence (IPV) traditionally has been perceived to be a ‘family matter’ by many of those in the medical profession. Nevertheless, the United Kingdom has made drastic changes to its national policies and understanding of IPV over the last 30 years in response to advocacy and campaigning by women’s rights groups. A recent example is the Domestic Violence Disclosure Scheme which allows the police to disclose to the individual his or her partner’s history of violent behaviour. Whilst such policies are commendable, it is argued that the medical profession remains an underutilised tool to help address the prevalence of IPV. Arguably, medical practitioners have a contribution to make, not only because of the impact it has on a victim’s health, but also because a physician may be a victim’s only point of contact with someone who can recognise and intervene in the situation. It is predicted that almost 80% of women who experience IPV in the United Kingdom have at one point sought assistance from healthcare services. Doctors can, in many cases, be a ‘lifeline’ for those individuals whose interactions with the outside world are barred by an abusive partner.

There is evidence to suggest that numerous doctors in the United Kingdom either do not know what to do when a patient discloses their history of IPV or are simply unwilling to take action. There have been numerous proposed solutions to resolve this issue, but none of the literature till date appears to explore the idea of a mandatory medical practitioner reporting scheme and its implementation in England and Wales. This paper aims to suggest a feasible mandatory reporting scheme for IPV before examining whether it could be legally and ethically justified.

This paper will first clarify the definition of IPV that will be used in this scheme. Secondly, an exploration of the vast array of mandatory medical reporting schemes that exist in different healthcare systems will be provided. Drawing from this research, a model has been created that would best fit the proposed definition of IPV and the current healthcare system in England and Wales. The legal and ethical justification in support of such a scheme will then be explored before a rebuttal is provided. Lastly, possible conditions and alternatives will be suggested and final conclusions will be drawn.

---

## Who has the right to justify euthanasia?

Atanas Anov & Silviya Aleksandrova-Yankulovska

Medical University-Pleven

Session 3  
Room 5

On June 17th 2016 Canada adopted a law that creates regulatory framework for medical assistance in dying. In the middle of September 2016 in Belgium was performed the first child euthanasia. The Dutch are considering to establish the first ever hospital for child euthanasia. This could happen within a year. With these events 2016 ended with ongoing classical debate concerning euthanasia and physician-assisted suicide.

Even though we are still in the very beginning of 2017 the world started talking about euthanasia once again but this time the debate takes an unexpected turn. In the beginning of January a citizen's initiative in Finland submitted 50,000 signatures in the Finnish Parliament (Eduskunta) placing the debate in political filed. There are politicians who oppose these ideas. Finnish doctors who are concerned with palliative treatment say that better training in palliative care would decrease all requests for active euthanasia and would improve palliative care services.

All of this raises the question "Who has the right to justify euthanasia (physicians, politicians, society or patients)?" It seems that the debate has left the field of bioethics and has entered the field of public health ethics. The aim of this report is to reflect on euthanasia as a public health problem.

Now that more and more countries around the world start talking about euthanasia laws and the fact that citizens demand such legislation, euthanasia is becoming more or less a public health problem. Let's look at euthanasia through the prism of the principles of public health ethics. The harm principles could be viewed from two perspectives. On one side, can we deprive a person from their life "in behalf of others", i.e. to relief societal or relatives' burden of terminal care? Or the harm to the individual would take the form of not allowing him to have euthanasia. Proportionality - euthanasia is beneficial for terminally patients because it would stop their suffering. Least infringement —palliative care as a least confiding measure requiring better palliative care training and services. Transparency - every government should argument why there is a euthanasia law no matter if the law allows or prohibits euthanasia. Physicians and public health experts should participate equally in creating or rejecting euthanasia legislation. The physicians are aware of the consequences from euthanasia legislation from medical perspective and public health professionals are aware of the social impact of such legislation. Reciprocity does not give us any guidance. It leaves us with the question who should be compensated and how. Necessity would not justify any law as long as there is effective palliative care.

In Germany every year the Bundestag (Germany's Parliament) commemorates victims of the Holocaust. This year for the first time the focus was on "the forgotten victims" of Na's euthanasia program. The relevant lesson from history teaches us why we should be careful with euthanasia legislation and politics.

## La enseñanza de la Bioética: una contribución al perfil de egreso de los estudiantes de Medicina

Carmen Astete<sup>1</sup> & Lorna Luco<sup>2</sup>

<sup>1</sup>Centro de Bioética. Facultad de Medicina Clínica Alemana Universidad Del Desarrollo Santiago de Chile; <sup>2</sup>Centro de Bioética. Facultad de Medicina Clínica Alemana Universidad Del Desarrollo. Santiago de Chile. Hospital Padre Hurtado.

Los exitosos avances científicos y tecnológicos han influido de manera importante en centrar el quehacer médico en los aspectos biológicos de las personas dejando en un plano secundario los aspectos sicosociales y culturales en la toma de decisiones clínicas. Los buenos resultados biológicos no han impedido que los pacientes se sientan insatisfechos con la atención que les prestan los profesionales, generando también frustración en los médicos por no lograr una relación clínica basada en la confianza y empatía. La medicina, una profesión tradicionalmente científico-humanista se ha “deshumanizado”.

La Bioética es una disciplina de corta trayectoria no obstante se ha reconocido en casi todas las escuelas de Medicina la necesidad de incorporarla como asignatura en el currículo para formar médicos asistenciales con una visión integral del hombre, con capacidad de diálogo, respetuoso de las diferencias y valores ajenos e investigadores responsables y conscientes de que no todo lo técnicamente posible es éticamente correcto (Delia Outumuro. *Acta Bioethica* 2008) y de esta manera volver a poner a la persona en el centro de la atención en salud y de la investigación.

No existe claridad de qué enseñar, cómo enseñar, debe haber un momento dentro del currículo o se debe enseñar transversalmente y quien debe hacerlo. Sí solo se enseña la Bioética en una asignatura y no se aplica durante las prácticas clínicas probablemente no tendrá impacto en la formación de los futuros profesionales.

Cada institución define para sus graduados un perfil de egreso que se ha definido como: “... la declaración institucional de los resultados de aprendizaje que certifican a los egresados de una carrera o programa como profesionales acreditados para desempeñarse exitosamente en el campo laboral, de acuerdo a su rol social y al sello distintivo que le otorga cada universidad...”.

Hemos realizado un análisis de cómo cada una de las competencias globales que se definen en los perfiles de egreso de las diferentes Facultades de Medicina apelan en parte a competencias del ámbito bioético y por lo tanto son una buena base para responder el qué se debe enseñar y de esta manera establecer los contenidos de los programas de las asignaturas de Bioética para la carrera de medicina y otras carreras de la salud.

El objetivo es ayudar a orientar el contenido de los programas de Bioética de manera que sean un aporte y tengan coherencia con la formación global de un profesional de la salud.

---

## **Blameworthy actions? On the anatomy of health-related actions people could reasonably be held responsible for**

Session 1  
Room 2

Kristine Bærøe<sup>1</sup>, Andreas Brekke Carlsson<sup>2</sup>, Andreas Brøgger Albertsen<sup>3</sup> & Cornelius Cappelen<sup>1</sup>

<sup>1</sup>University of Bergen, <sup>2</sup>University of Oslo; <sup>3</sup>University of Århus

Health-related behavior that has to do with nutrition, level of physical activity and risk of becoming contagious correlate largely with the local and global burdens of diseases. At the same time, healthcare resources are not unlimited; in fact, especially in low- and middle-income countries, health resource scarcity is frequently a huge societal problem, resulting in severe and prevalent healthcare needs going unmet. If people can influence their own health situations, then blaming those who make no efforts to avoid poor health or who even seek behaviors that increase their risks of needing healthcare may seem morally appropriate. Moreover, it might seem reasonable to reduce their entitlements on otherwise available services, for example in terms of taxes on unhealthy, life-style related choices, increased out-of-pocket payments or longer waiting time. In fact, such moral intuitions support not only philosophical approaches to political theory, such as luck egalitarianism, but also practical politics of national health authorities in various ways.

In this paper, we present a philosophical approach to this issue. We apply conceptual analysis to clarify how responsibility link to health related actions. In doing so, we rely on a crucial conceptual distinction in the philosophical literature between being responsible and holding someone responsible. We argue that even though we might be considered responsible and blameworthy for our health-related actions, there might still be well-justified reasons for not considering it reasonable to hold us responsible by giving us lower priority in terms of sanctions.

We then transform these philosophical considerations into practical use: we assess general features of health-related actions and corresponding healthcare needs and identify clusters of structural features that even adversely affected patients cannot reasonably deny constitute actions they could be held responsible for. These results would be useful for politicians or healthcare administrators who are considering introducing personal responsibility for health as a criterion for setting priorities in healthcare distribution.

Therefore, we summarize the results in a framework that can be easily consulted by anyone who will test the applicability of the personal responsibility criterion on certain healthcare needs.

# Equitable healthcare: On the potential impact of politicization, bureaucratization and medical standardization of healthcare distribution on social health inequality

Session 2  
Room 5

Kristine Bærøe<sup>1</sup>, Inger Lise Teig<sup>1</sup> & Benedicte Carlsen<sup>2</sup>

<sup>1</sup>University of Bergen; <sup>1</sup>Uni Rokkan Research Center, Bergen)

With this paper, we wish to increase the awareness of how governing instruments (with justified aims) may influence and reinforce health inequity at the point of care. We wish to discuss the potential impact governing instruments that are shaping healthcare systems may have on socioeconomic disadvantaged patients groups' access to healthcare even in the contexts of publicly funded and universally accessibly healthcare.

An adequate analysis of potential barriers to access must aim to reveal characteristics of healthcare systems that might pose challenges to equal access given unequally distributed capacities to fully take entitled advantages of the services. There are at least three arenas to look for such barriers. Firstly, it is widely agreed that main causes to health inequity is found outside the healthcare system, i.e. in income, education and environment. Secondly, barriers to equitable healthcare can be found within the healthcare system itself. Healthcare workers could be barriers to equal service within the system if they lack education on the social determinants of health, how health inequity may occur and how it could be tackled at the point of care. Moreover, cultural discrepancies between healthcare providers and receivers may block understanding and influence decision-making. Thirdly, healthcare systems and institutions can be expected to create barriers to health equity if they are shaped by mechanisms or governing instruments that require skills and resources certain patient groups typically lack, such as money and education, in order to fully benefit from its services.

Based on normative theories, we simply take it as our starting point that unequal access to healthcare systems and its services that correlate with peoples socioeconomic status is inequitable and should be avoided by the shaping of the healthcare systems in the first place. To realise a healthcare system that actually promotes equitable access to its services we need knowledge about formative barriers. More precisely, we want to discuss structural ways the implementation of a limited set of such instruments, i.e. political, administrative and medical standardizing, may influence socioeconomic disadvantaged patients' access to healthcare.

---

# Conceptualizing health to reduce health inequality

Session 2  
Room 5

Kristine Bærøe & Berit Bringedal

<sup>1</sup>University of Bergen, Norway; <sup>2</sup>Berit Bringedal, Institute of Studies of the Medical Profession, Norway

**Background.** The World Health Organization defines health as “... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” The definition has been criticized for various reasons. It does not reflect that people can adapt to their conditions and feel healthy despite chronic disease or disability; it cannot be operationalized; it is limitless and may therefore contribute to unjustified medicalization; and the definition is insensitive to distinctions between the severity of health deficiencies and correlating distinctions in claims for health care. Time has come to revise this definition.

**Discussion.** We argue that there is a need for a concept that allows for subjective experience of health as well as solving the shortcomings listed above. Moreover, given the epidemiological knowledge of social health inequalities across and within nations, we contend that time has come to modify the individual-centered definition of health with a moral-political understanding of health. A ‘moral-political’ conceptualization implies not only a morally justified definition, but also that it can be applied to influence the distribution of health in a society.

**Method.** The approach is theoretical-analytical; the discussion is based on moral theory, empirical evidence of health inequality and analytical reflection.

**Summary:** We suggest a moral-political concept of health that we show incorporates all of the mentioned concerns while revolving around a specified threshold of human functionality. This threshold is set at the level of functionality that correlates with absence of disease and infirmity.: “Health is the physical and mental capacity required to realize individual and social rights and duties, and to participate in individual and social activities that correlate with further lack of disease and infirmity” The definition is dynamic in two ways: If implemented in distributive policies, it can influence allocation of healthcare resources to provide people with equal opportunities to benefit from activities that are observed to correlate with further absence of disease and infirmity. Such activities are e.g. education, work, physical activity and friendships. In this way it reduces health inequality. Further, correlations between specific activities and future health status may change over time and our proposed definition is flexible with respect to such changes.

---

## Ethics of full disclosure in the presence of presumable nocebo effects

Juan Pablo Beca

Centro de Bioética, Facultad de Medicina, Clínica Alemana - Universidad del Desarrollo

When prescribing a medication the physician ought to give truthful information about the likely benefits but also about the potential adverse effects to that medication. Only then the competent patient will be able to make his or hers autonomous decision. However, the mere expectation of adverse effects may precipitate the corresponding symptoms or lead to their exacerbation. This is called nocebo, a negative mirror of the positive placebo effect that is a well-known therapeutic reaction. Unlike placebo the patient who develops nocebo symptoms can then be harmed due to psychological factors.

Recent reviews of nocebo effects show that they occur frequently and are clinically significant yet often go unnoticed. It has also been stressed that this clinical situation brings guiding principles in medical ethics into conflict: the moral obligation to disclose all possible effects of the prescribed drug, in front of the duty to avoid the harm of side effects that are likely to occur in a particular case. In other words, the physician faces a dilemma between the due respect for autonomy and the duty of do-no-harm (i.e. non-maleficence). A common response to this dilemma has been to carry out a balancing approach to the bioethical principles in conflict and to propose that, when the risk of nocebo effects attached to disclosing information about side effects is high, it can be justified to vulnerate—to some extent—the patient's autonomy by concealing that information.

In this presentation, we concur with the view that full information about potential side effects can be reduced if there is a risk for a specific patient. We suggest, from a patient-centered perspective, that the physician can be justified to limit information for the sake of avoiding negative outcomes in certain contexts. Admitting that this option could be regarded as paternalism, it is based on a notion that patients need to be supported, although not guided or conducted in their decision-making. In this sense we discuss conceiving the principle of autonomy more as a relational than an individual concept, when applied in practice.

In the discussion on the ethical dilemma between full disclosure and concealing information to avoid harm there is a requirement to specify or balance bioethical principles, however in practice non-maleficence is often prioritized over autonomy. We suggest handling the conflict between these principles by appealing to theoretical approaches that assign priority to non-maleficence. For example Diego Gracia's view that non-maleficence corresponds to the public sphere of social duties and thus imposes obligations that rank over autonomy, which is an expression of the private domain of individual moral values. In this respect, we also consider Danner Clouser and Bernard Gert's proposal to formulate non-maleficence as a moral rule while understanding autonomy as a moral ideal that should not be imposed at all times.

---

## **Sociotechnological background of personalized medicine development: better life for better humans?**

Session 2  
Room 2

R.R. Belyaletdinov

Institute of Philosophy RAS, Moscow, Russian Federation

The paper discusses the features of the becoming of personalized medicine as a socio-technological artifact. From the point of view of the theory of science and technology studies values of society have a fundamental influence on the development of technology. Research project as a collection of working technologies turns socio-technological artifact if it is recognized by society. Even non-functioning technology can be regarded as a working ones if they receive public recognition.

Supporters of personalized medicine suggest that people with certain features detected by genetic testing, respond better to certain medications. So pharmaceutical company Roche had to its credit the drug Xeloda, which, once in the body, becomes active under the influence of specific ferment found only in some patients.

Personalized medicine is based on the latest achievements of science and technologies, not only biomedical ones, but also information technologies related to the storage, analysis and construction of large volumes of information processing algorithms. In this regard, the development of personalized medicine is associated with technical difficulties. Biological big data make new synthesis and biological patterns set via OMIC, but they also carry a large number of errors at storage and processing of large volumes of information. Nevertheless, this does not prevent to consider personalized medicine as a promising project that implements the ideas about the future of medicine.

Formation of personalized medicine is invited to consider how to develop the idea that technological determinism acts as a socio-humanistic values, and personalized medicine represents a projection of the socio-humanitarian technological determinism to conventional medicine. (The paper is prepared with support of project funded by RHF, Num. 15-18-30057).

---

## **Surgeons and research: the context and concept of surgical innovation (1)**

Session 2  
Room 4

Giles Birchley<sup>1</sup>, Richard Huxtable<sup>1</sup>, Jon Ives<sup>1</sup>, Noah Howes<sup>2</sup> & Jane Blazeby<sup>2</sup>

<sup>1</sup>Centre for Ethics in Medicine, University of Bristol; <sup>2</sup>Centre for Surgical Research, University of Bristol

The context of surgical innovation. While the institutions of medical research and medical practice have been separated in many nations for more than a century<sup>2</sup>, surgical practice has followed a different path. Formal research, especially in the form of randomised control trials, remains relatively rare in surgery compared to medicine. Surgical innovation, however, is common and appears to straddle the research/practice boundary. Such innovation encompasses various practices, including: devising responses to normal anatomical variations in patients; contriving new techniques in acute situations where existing methods fail; systematically testing

new surgical instruments; using familiar instruments in new ways; addressing hitherto neglected diseases; and refining the technique, outcomes or efficiency of existing interventions. Some commentators suggest surgical practice has a closer relationship with innovation than other branches of healthcare<sup>3</sup>, with some claiming that the advancement of surgical practice is attributable to its innovative nature<sup>4</sup>.

The challenge of conceptualisation. The term ‘innovation’ tends to carry overtones of personal enterprise and entrepreneurialism. This has enormous cultural currency in a society that prizes these characteristics, both as drivers of economic prosperity and as laudable personal traits<sup>5</sup>. Yet some caution that innovations are not always progressive or beneficial<sup>6</sup>. Ethical challenges in surgical innovation are recognised: innovations carry unknown risks. Surgeons may foresee these but optimism-bias may impair their judgement. The beneficiaries of innovation may vary: although many surgical advances are focused on patient benefit, these may not be felt by the patient on whom the innovation is tried; innovations also include improvements in efficiency and technique where benefits accrue to future patients, wider institutions or national and international economies. Such advances may be accompanied by peer approval, and historically have conferred both professional recognition and financial reward on successful innovators. Moreover, innovative practice is often ad hoc and of variable efficacy. Since failed innovations are not reported, the deleterious impact of failed innovations is difficult to assess. Attempts have been made to devise and promote a regulatory framework to answer some of these challenges<sup>7</sup>, and recent research has been published to help surgeons identify innovation in their own practice<sup>8</sup>. However, the way we conceptualise innovation and its developmental stages will vary according to the use to which the concept is directed, and this complicates conceptual work.

We suggest a conceptualisation of surgical innovation requires the detailed investigation of both the concept and the context of “innovation” and the attendant phases of innovative practice. In this presentation, we present the findings of a literature review and conceptual analysis focused on this task. While targeted at surgical innovation, our findings should facilitate subsequent reflection on the (bio)ethics of innovation in general, its evaluation and implementation. As such, conceptualising and identifying innovation is important for bioethics, so that assessments can be made not only of its ethical implications, but also of the appropriate professional or regulatory requirements that should govern practice in diverse areas of healthcare.

<sup>1</sup>This study was supported by the NIHR Biomedical Centre at the University Hospitals Bristol NHS Foundation Trust and the University of Bristol. The views expressed are those of the authors and not necessarily those of the UK National Health Service, National Institute for Health Research, or Department of Health.

<sup>2</sup>Ben-David J. Roles and Innovations in Medicine. *Am J Sociol* 1960;65(6):557-68.

<sup>3</sup>Riskin DJ, T Longaker M, Gertner M, et al. Innovation in surgery - A historical perspective. *Ann of Surg* 2006;244(5):686-93.

<sup>4</sup>McCulloch P, Altman DG, Campbell WB, et al. Surgical Innovation and Evaluation 3 No surgical innovation without evaluation: the IDEAL recommendations. *Lancet* 2009; 374(9695):1105-12.

<sup>5</sup>Pickstone JV. *Medical Innovations in Historical Perspective*. London: MacMillan Press 1992:1-17.

<sup>6</sup>Rogers E. *Diffusion of Innovation*. 5th ed. London: Free Press 2003: 1-38

<sup>7</sup>McCulloch P, Altman DG, Campbell WB, et al. Surgical Innovation and Evaluation 3 No surgical innovation without evaluation: the IDEAL recommendations. *Lancet* 2009; 374(9695):1105-12.

<sup>8</sup>Hutchison K, Rogers W, Evers A, et al. Getting Clearer About Surgical Innovation: A New Definition and a New Tool to Support Responsible Practice. *Ann Surg* 2015;262(6):949-54

<sup>9</sup>Johnson J and Rogers W. Innovative surgery: the ethical challenges. *J Med Ethics* 2012; 38: 9-12.

---

## Ethics recommendation for the big data's managing for a population-based health monitoring project

Session 1  
Room 1

Luciana Caenazzo<sup>1,2</sup> & Pamela Tozzo<sup>1</sup>

<sup>1</sup> University of Padova - Padua - Italy; <sup>2</sup>Fondazione Lanza- Padua - Italy

Nowadays, we witness the emergence of a new phenomenon in science and technology, that is the convergence of technologies and scientific disciplines: singly, each of them has a large potential to change society and mankind, but combined they represent a more powerful source for even bigger changes.

This technological convergence reinforces the development of the technologies involved, creating new application domains by their combination, with an important influence in medical sciences.

In this developing field, we can distinguish among different pathways, but particularly in the field of public health we see different emerging projects regarding record-linkage between big data archives of various origins (commercial, economic, institutional, social networks, etc.) resulting in the definition of subsets of the population to be considered at higher risk of developing a particular disease, and record-linkage between electronic administrative health archives, which could be processed using disease-specific algorithms to identify individuals with disease in a population.

The increasingly widespread use of digital recording in administrative, commercial and social networks is opening up new and unpredictable scenarios, that might also influence the definition of disease in a digital society. Some Authors have addressed this issue, examining the feasibility of record linking between health-related archives and other electronic archives such as Facebook, Twitter, blogs, online shopping habits, GPS recordings of individual mobility, personal devices monitoring physical exercise, and so on. By developing appropriate algorithms, it would be possible: to identify subsets of the population at higher risk of developing diseases, to ascertain whether distances between homes and drugstores or hospitals influence people's health profile, to see whether the characteristics shared by Facebook friends influence their individual health profiles, and so on. The possibilities are limitless, and inevitably give rise to ethical aspects in relation to human rights.

We present the results of the project "Ethics and Emerging Technologies: a Population-based Health Monitoring Project": this project has been conducted by

an interdisciplinary research group and it seeks to identify and address those ethical issues related to the integrated use of new technologies (neuroscience, nanotechnology, genetics, computer science, etc...) in the medical-clinical field, in order to achieve a global management of the overall health of the individual within the community and its environment.

Our objective is to draw up ethical guidelines for managing the potential and critical issues raised by the convergence of the study of the results coming from epidemiological data and health records, genetics, nanotechnology, and neuroscience concerning the individual. We deepened different ethical aspects related to the value of data, privacy, different consent forms and its modality, priorities and urgent health needs of the population, management of prevention campaigns, intervention planning and resource allocation.

---

## How are we making a crucial decision? A Reflective Judge's reprise

Session 1  
Room 1

Andrea Castagnoli

“Cà Foscari” University of Venice

Changing in scientific environment puts researchers under more pressure because technologies, knowledges and tools are now involved in solving issues, almost impossible just a couple of years ago. For these reasons, I firmly believe that an interdisciplinary approach may be applied to achieve a methodology useful to enhance either decision-making processes and sanitary protocols by specialists. If we understand the two fundamental moments of the first, we will be able to improve the second one. My dissertation is focused on an original reprise of Kantian Reflective Judgement in a bioethical context, with the chance to join an innovative and critical viewpoint in complex cases and grey areas. As a results, I would show up these main landmarks:

1. Why Reflective Judgement? In our societies, doctor-patient relationship is usually a hurry race where the first one has to figure out a diagnosis as soon as possible and categorise the second one in a specific protocol. This way to operate could be also called determinative judgement, using a kantian language, because a particular case is subsumed under a general rule. On the other hand, reflective judgement can change the perspective and avoid a reductionist approach without losing a scientific fundament. Moving from the singular to find what is the best in a universal context when facing with an hard case, may give a crucial improvement in the decision-making process and in granting a primary role to the patient.
2. Ethical decision-making. A thought based on a coming and going between universal rules and singular cases should be either interdisciplinary and intradisciplinary, especially in more complex cases such as rare diseases. This is why bioethics can give an essential support in developing a dialogue between medical specialists to catch details usually consider less significant to reach a

diagnosis. Moreover, a constant exchange with bioethicists, sanitary staff and parents can build a framework full of other elements not directly connected with the medical science.

In conclusion, I would underline how important is a reflective judgement's reprise into bioethics field in avoiding a mechanical reductionism but also a naive relativism. Likewise, a clarification of each paradigmatic situations where the singularity does not have a universal rule and it is connected directly with the exemplary concept. Further, in my opinion, is necessary exploring a specific scheme with problem-solving patterns to merge hermeneutical approach and other studies around important details, like Peirce's or Ginzburg's view, which can confirm a distinction between determinative and reflective judgement, without an opposition because only the most complicated cases required a prospective change such as arguments about freedom of choice and the contingency in the contemporary debate.

---

## **An ethical approach to ER Facilities in Turkey for Syrians Under Temporary Protection**

Orcun Cil, Sefik Gorkey & Kursat Epozturk

Session 1  
Room 3

Syrian civil war started approximately 6 years ago and Syrians begin to come to Turkey in April 2011. From that time, nearly 3 millions of people from Syria have been recorded according to Turkish government statistics. Temporary protection status and some other legal national arrangements provides refugees to access almost all health facilities. In Turkey, ER departments are one of the most important departments for provide this facilities. This importance comes from not only by the emergency medicine care system has vital for every people, also Syrians usually comes ER services for most of their medical problems.

As a physician working in ER service, I'll discuss ER facilities for Syrian patients in Turkey with my personal experiments from ethical perspective.

---

## **La prescripción en Atención Primaria de Salud y la sostenibilidad de sistemas sanitarios**

M<sup>a</sup> Constanza Colchero Calderón

Sociedad Andaluza de Investigación Bioética (SAIB)

Session 3  
Room 7

La prescripción en recetas suele ser culmen del proceso diagnóstico en la atención primaria de salud (APS). Puede ser considerada un acto burocrático más en la APS<sup>1</sup>: recetar, renovar tratamientos crónicos, continuar la prescripción de otros especialistas o acceder a la demanda de los ciudadanos que consideran tener derecho a fármacos más baratos.

CONTEXTO. El sistema sanitario tiene una influencia menor como factor de salud. Sin embargo, demanda unas necesidades de financiación creciente. La atención hospitalaria genera el 61% de los gastos, la APS en torno al 14% y el gasto farmacéutico poco más de 15%<sup>2</sup>. Existen muchos esfuerzos orientados a controlar el

gasto que permita la sostenibilidad del sistema nacional de salud, constatándose un descenso en la última década con un repunte final<sup>3</sup>.

La prescripción obliga al médico a actuar con pericia profesional y nivel ético, garantizando la calidad asistencial<sup>4</sup>. Muchos dilemas éticos pueden generarse a la hora de la prescripción<sup>5</sup> Para valorarla en un momento concreto, podemos utilizar el método casuístico de Jonsen<sup>6</sup>, de modo analógico, en relación con la pregunta: ¿Cómo debo realizar una prescripción ética?

Caja 1ª “INDICACIONES”. La prescripción debe adecuarse a la ciencia médica actualizada. La medicina basada en evidencia ayuda a evitar la maleficencia de ser pródigos en la medicalización<sup>7</sup>. Pasos adelante los encontramos en los modelos de la medicina basada en la persona o el propuesto por Albert Jovell<sup>8</sup>, que conjugan el razonamiento clínico prudente con la incertidumbre, centrado en la persona. Otros campos de adecuación son la deprescripción por seguridad, y el abordaje del paciente crónico con polifarmacia.

Caja 2ª “PREFERENCIAS”. Las experiencias personales del médico<sup>9</sup> y del paciente conllevan al consentimiento informado, al rechazo de tratamiento fútil, a la toma de decisiones compartidas, etc. La atención longitudinal, propia de la APS imprime dinamismo a la prescripción.

Caja 3ª “CALIDAD DE VIDA” (de la prescripción en este caso). Ayudan a la calidad de la prescripción, las recomendaciones de agencias evaluadoras, servicios farmacéuticos del sistema sanitario, los colegios profesionales, sociedades científicas, etc. Los programas de módulos de Receta electrónica facilitan la prescripción. Sin embargo, accesibles a todos los especialistas, corren el riesgo de convertirse en embudos de múltiples prescripciones sin seguimiento. Destacar la obligación del profesional en la mejora de esos programas<sup>10</sup>.

Caja 4ª CIRCUNSTANCIAS. Pueden ser muy diversas y en todos las direcciones: finalidad de la prescripción curativa, paliativa o satisfactiva, incentivos de productividad<sup>5</sup> en el propio sistema sanitario, participación en estudios que debe estar aprobada por Comité de ética de investigación, sistema de subastas de fármacos o plataformas y desabastecimiento de los mismos, discontinuidad asistencial por empleo precario o falta de recursos adecuados<sup>11</sup>, bonanza o crisis económica, etc.

CONCLUSION. El acto médico personal de la prescripción puede redundar en la sostenibilidad del sistema. Por tanto, precisa del ejercicio de una ética de la responsabilidad<sup>12</sup>. La misma que debe orientar al cuidado del paciente y su bien, con resultados en salud, en mejores profesionales, y una correcta adecuación de recursos.

#### Bibliografía

<sup>1</sup> Cubí Monforta R, Faixedas Brunsomsb D. Viabilidad de la receta electrónica en España. *Aten Primaria*. 2005;36:5.

<sup>2</sup> ESTADÍSTICA DE GASTO SANITARIO PÚBLICO 2014: Principales resultados. Edición mayo 2016. Ministerio de Sanidad, Servicios Sociales e Igualdad. Gráfico 4. Gasto sanitario público consolidado según clasificación funcional. Estructura porcentual. España, 2014. Pag. 5

<sup>3</sup> Ministerio de Sanidad, Servicios Sociales e Igualdad. [consultado en línea el 11 de marzo de 2017] <https://www.msssi.gob.es/profesionales/farmacia/datos/home.htm>

<sup>4</sup> Código de Deontología Médica, 2011. Art. 23.

<sup>5</sup> Moya Bernal A. Ética de la prescripción. *Inf Ter Sist Nac Salud.* 2011;35:57-63.

<sup>6</sup> Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics.* Mc Graw Hill, Inc. 1992. [consultado en línea el 13 de junio de 2016] <http://eduserv.hscer.washington.edu/bioethics/tools/ceintro.html>

<sup>7</sup> Altisent R. “David Sackett”. *Diario médico.* 2015 [consultado en línea el 23 de junio de 2015]

<sup>8</sup> Modelo afectivo-efectivo de Albert Jovell. [consultado en línea el 10 de marzo de 2017] <http://www.foropremiosalbertjovell.es/el-modelo-afectivo-efectivo>

<sup>9</sup> Práctica basada en la experiencia. *Clínica razonable blog.* Área integrada Talavera de la Reina [consultado en línea el 10 de marzo de 2017] <https://clinica-razonable.wordpress.com/2016/06/21/de-la-medicina-basada-en-la-evidenciaala-practica-basada-en-la-evidencia-un-desarrollo-transdisciplinar>

<sup>10</sup> En Andalucía se ha producido una mejora importante en el módulo de prescripción electrónica asociado a DIRAYA, debido a las amplias protestas y propuestas de profesionales que llevaron a constituir un grupo de trabajo integrado por profesionales del Servicio andaluz de salud y de sociedades científicas [consultado en línea el 20 de septiembre de 2016] [http://www.samfyc.es/index.php?option=com\\_content&view=article&id=1075:2016-09-20-06-38-59&catid=34:listado-de-articulos&Itemid=74](http://www.samfyc.es/index.php?option=com_content&view=article&id=1075:2016-09-20-06-38-59&catid=34:listado-de-articulos&Itemid=74)

<sup>11</sup> Porras P. “¿Qué queremos los médicos de familia? ¿Seguimos queriendo lo mismo que queríamos hace años?” Editorial. *Med fam Andal Vol. 16, N°.3,* noviembre 2015

<sup>12</sup> Declaración sobre ética y responsabilidad en la sostenibilidad del sistema nacional de salud. Declaración de Zaragoza 2016. Comité de Bioética de España. CBE. [consultado en línea el 10 de marzo de 2017 [http://www.comitedebioetica.es/files/documentacion/es/declaracion\\_sostenibilidad\\_sistema\\_nacional\\_salud.pdf](http://www.comitedebioetica.es/files/documentacion/es/declaracion_sostenibilidad_sistema_nacional_salud.pdf)]

---

## No Health without Mental Health. Broadening the Scope of Bioethical Inquiry.

Paolo Corsico

Centre for Social Ethics and Policy, The University of Manchester; Neuroscience Ethics and Society team, University of Oxford

Session 3  
Room 6

‘No health without mental health’ is the title of a policy document published by the Department of Health (DH) of the British Government in 2011. The ambitious goal set up by the DH at that time was to support and implement policy actions that would work towards parity of esteem between mental and physical health services. Indeed, not only was this revolutionary approach grounded in clinical or health economics considerations, but also in the ethical principles of justice, fairness, and promotion of human rights. Promoting awareness and improving access to mental health services constitute an ethical challenge for liberal, democratic societies, and a moral duty towards the improvement of people’s well-being and quality of life.

Taken altogether, mental, neurological and substance use disorders represented, in 2010, the leading cause of estimated global Years Lived with Disability (YLDs), while mental disorders accounted for the largest proportion of Disability-Adjusted Life Years (DALYs) amongst mental, neurological and substance use disorders. If a primary scope of bioethical inquiry is to support the implementation of justice in healthcare and promote individuals' well-being, then it is pivotal that mental health be included among the most relevant areas of investigation in bioethics. If there is no health without mental health, I argue, there should be no health care ethics without mental health ethics.

In this presentation, I will try to assess in what ways, and to what extent mental health can become central in our understanding of health care ethics. I will argue that concepts with a long-standing tradition in medical ethics, such as autonomy, beneficence, and informed consent could survive a theoretical shift towards mental health, only if they were appropriately translated into the mental health domain. In addition, given the ongoing integration of neuroscientific findings in psychiatry, I will argue that traditional boundaries amongst different areas of ethics research, such as psychiatric ethics, neuroethics and care ethics, should be overcome towards an integrated approach, which could situate mental health patients and service users' needs at the core of our reflections. Lastly, I will suggest that an empirical exploration of relevant stakeholders' perspectives may help us identify those needs, and assess the values at stake. In order to substantiate these arguments, I will focus on the management of psychotic disorders in the UK context. I will introduce a qualitative study on the ethical issues in novel neurobiological approaches to psychosis and schizophrenia, which takes place in NHS mental health Trusts in England. This, with the aim to demonstrate how empirical research in psychiatric ethics can contribute to enrich the bioethics endeavour.

---

## **Undoing Capacity: Applying the Capability Approach to Pediatrics**

Session 3  
Room 4

Eva De Clercq & Bernice Elger

Institute for Biomedical Ethics - University of Basel, Switzerland

Although children generally do not have legal competence, ethical guidelines (e.g. The United Nations Convention on the Rights of Children (1989) increasingly emphasize the importance of involving minors in healthcare decisions at a level commensurate with their age and capacities.

Capacity is usually perceived of as a mental ability which somehow resides within the person. There is growing discontent with this cognitivist model of capacity (and with the tools developed to assess it) as it tends to discriminate 'vulnerable' groups (e.g. cognitively impaired elderly, children, women) whose illness, age or gender seem to compromise the ability to make rational decisions. This means that capacity functions as a normative concept which weakens children's position in the medical encounter. In order to do justice to the children's point of view, we need to 'undo' this reified understanding of capacity and highlight that this concept always operates within a particular social and cultural framework.

It is argued that the capabilities approach, as developed by A. Sen and M. Nussbaum, offers a promising framework to theorize and improve the decision-making process in pediatrics. The core claim of this approach is that capabilities denote the real opportunities a person has to achieve functionings, i.e. the various things a person is able to be and to do. For example, the capability of decision-making is both necessary to, but different from the actual level of involvement. In order to participate, children need to have the opportunity to choose, but their actual choices regarding their participation might differ. Further the conversion of capabilities into functionings is influenced by personal (e.g. physical condition), social (e.g. family dynamics) and environmental (e.g. hospital culture) conversion factors that might have a positive or negative impact upon this process.

There are several advantages of using capabilities as the metric for children's involvement in health care decision-making. The capabilities approach, in fact, is not exclusively rational, but looks for those external elements, practices, policies and relationships which can (dis-) empower children's participation. This means to shift the focus away from a deficit model of capacity (lack of personal 'cognitive' property) to one of a common responsibility, where all parties involved in the decision-making process contribute to the child's (developing) capabilities. In this way, the capability approach is also more reflective of the pediatric context in which there are always three actors involved in the decision-making process, the child, the parent and the health care professional.

---

## **How to realize dignified care for female Islamic patients? A qualitative study of intercultural care experiences in maternity care units in Flanders, Belgium**

Session 3  
Room 1

Liesbet Degrie, Chris Gastmans, Bernadette Dierckx de Casterlé & Yvonne Denier  
KU Leuven, Public Health and Primary Care, Centre for Biomedical Ethics and Law & Zorgnet-Icuro, Care Network Flanders, Belgium

Although globalization, migration and multiculturalism raise many debates within contemporary societies, the question on how to realize dignified care in this intercultural reality is still underexplored.

According to the WHO, healthcare services should ensure culturally appropriate care (WHO, 2010). Nevertheless, international research still shows inequalities, barriers in access and a lower quality of care for ethnic minority patients. Many intercultural challenges are still visible in daily care practices. Especially in the hospital setting, when care is acute and inevitable, the realization of dignified care is compromised by intercultural factors such as, language and cultural barriers, differences in understanding health and treatment, negative attitudes, lower health literacy in ethnic minority groups and scarcity in hospital resources. Against this background, caregivers and patients have to try to find an ethically founded dignified answer to a situation of human vulnerability.

For the time being, the intercultural challenge in providing dignified care is aggravated by the lack of insight in the ethical aspects of intercultural care, combined with a lack of ethical guidelines for health care practice. Moreover, international

literature lacks insight in the care experiences from the perspective of ethnic minority patients themselves. Nevertheless, such insight is crucial in finding an answer to the fundamental question on how to provide good intercultural care.

We aimed to fill this gap by performing a qualitative study on the intercultural maternity care experiences from the perspective of female Islamic patients themselves. Female Islamic patients are especially vulnerable when receiving care during this perinatal period. The Grounded Theory approach is used for the data collection and data analysis. Semi-structured interviews are conducted with female Islamic patients, midwives and gynecologist in Flanders. The interview guides are based on previous systematic literature review (Degrie et al., 2017).

From the literature review, we have learned that the intercultural care encounter can be presented as a meeting of two different cultural contexts of care, as a dynamic process of establishing a meaningful care relationship between caregiver and patient and as a process of balancing between the two different cultural contexts of care. We also learned that this process of balancing between two cultural contexts of care is essentially influenced by various mediators such as: communication, the role of family members, the role of the hospital's organizational structure and the presence of humanity in care.

At the moment of the EACME's Annual Conference in September 2017, we will present the findings from our own empirical research, i.e. from semi-structured interviews (with appr. 25 patients, 10 gynecologists, and 10 midwives) and discuss how we can ethically reflect on these results in order to find an answer to the fundamental question on realizing dignified care in the intercultural hospital setting.

---

## **From clinic to community: Teaching, supporting and doing ethics in care work outside hospitals**

Session 1  
Room 5

Michael Dunn  
University of Oxford

Ethics education, well-established in hospitals, may also be organised to serve those working in the community. While it is axiomatic that health care work is ethically challenging, health care ethics, as an enterprise, has paid far less attention to the ethics education needs and challenges of community professionals who do 'care work'. For nurses, physicians, social workers, health care assistants, health visitors, case managers, and others who provide care to people with serious chronic conditions in home, community-based, and ambulatory care settings, ethics consultation services may be non-existent, or accessible only via hospital admission. Given the realities of ageing societies, and the migration of many medical interventions and forms of care into non-medical settings, what does clinical ethics owe to those who do care work? This presentation will draw on research conducted within an international health care ethics capacity building project to explore:

1. ethics in the community & the special challenges of ethical decision-making and support in the community will be considered, drawing on lessons learned

from a recently completed project in Singapore, and other research into the challenges of supporting people with long-term and chronic health conditions outside the hospital setting. Explicit attention will be paid to community-based ethical decision-making in the European context.

2. ethics done communally & the reality of shared ethical decision-making among different professional actors and “informal” caregivers, including paid workers and family members, will be examined. The duties and obligations of different caregivers and the implications of these duties for ethical responsibility, education, and support will be highlighted.
3. modelling ethics support for the community & the ethical distinctiveness and practical features of community-based care raises questions about whether and how standardised approaches for ethics consultation and committee work can be developed for the community setting. A community networking approach to these challenges will be considered.

---

## **Beyond recovery: towards rights-based mental health care**

Session 3  
Room 6

Francisco José Eiroa-Orosa  
University of Barcelona

**Introduction:** Recently, mental health recovery, among other transformative movements, has begun to promote citizenship, both as a participation tool and as a therapeutic intervention, and as social prescription to broaden the range of therapeutic options in the practice of primary and mental health care. The latter, has been achieved by strengthening the links between health services and community resources.

**Method:** In the framework of these transformations, we present preliminary results of an educational research-action project that seeks to promote shared analysis and open dialogue about the values that are at stake in mental health care. Together with user associations, family members and the Obertament campaign against stigma in mental health, we have developed training activities based on values promoted by “first person” associative (also known as consumers’ or survivors’) movements and psychiatric rehabilitation. These values include psychosocial recovery and empowerment as extended concepts in contrast with the mere reduction of symptoms, and the promotion of rights and active citizenship. A distinctive feature of this project is that it offers training with the participation of people who have experienced a mental health problem, that is, a series of training activities offered by mental health treatment experts as well as by the people who themselves had the experience of a mental disorder.

**Results:** Our research group administered a scale on Professional Attitudes in Mental Health at the beginning and end of several training activities. The results of the evaluation of these trainings with mental health professionals and students show statistically significant reductions in stigmatizing attitudes and the paternalism with which different mental health interventions are carried.

Conclusions: The final aim of the project is to provide tools to clinical staff to be able to put their own values on the table and establish a sincere dialogue with the users of mental health services that may lead to the promotion of shared spaces for recovery.

---

Session 3  
Room 1

## **Gender, equality and the steepness of the social gradients in health**

Carina Fourie

Department of Philosophy, University of Washington; Bioethics and Humanities, Medical School, University of Washington

A consistent association exists between increments of health and increments of social status, and it continues to exist across a variety of measures of both health and of social status. This association applies strongly to both men and women across numerous countries, developed and developing, and is commonly referred to as ‘the social gradient(s) in health’.

A puzzling corollary is that social gradients in health often appear to be steeper on average for men than they are for women. Put another way, the men who are worst off tend to be much worse off in comparison to the men who are better off, than the worst off women are in comparison to the better off women. It is puzzling partially because women seem to be more likely than men to be exposed to negative social determinants of health through discrimination and disadvantage. While it is not obvious how women’s disadvantage should translate into the steepness of the gradient, it is also not clear why there should be greater equality in health among higher and lower status women than among higher and lower status men. I will refer to this as the ‘Steepness Problem’.

This problem does not appear to be garnering quite as much attention as I think it should be in the empirical literature. More importantly, for the purposes of this paper, which identifies as a work of normative applied ethics it seems, thus far, to be neglected in the bioethics and health justice literature.

My aim in this paper is to identify two normatively relevant implications of the Steepness Problem. I do not claim that these are the only normative implications, but as a preliminary attempt to analyze the Steepness Problem ethically, I will raise these two initial concerns. I raise the concerns that in light of the Steepness Problem, some attempts to flatten the gradients in health could disproportionately favor men, and some attempts to flatten the inequalities in social status behind the social gradients in health will leave intact or reinforce gender biases. In the final part of the paper I consider what we can learn about status and equality and the theories that should underlie health justice, from the Steepness Problem. I focus particularly on how the Steepness Problem can be understood plausibly using a framework that distinguishes distributive egalitarianism from social-relational egalitarianism.

---

## **Egg-freezing for age-related reasons: social expectations versus medicalisation of life**

Session 1  
Room 2

Véronique Fournier & Laurence Brunet

Centre d'éthique clinique , Hôpital Cochin, Assistance Publique-Hôpitaux de Paris

In France, access to reproductive technologies has been strictly regulated by the bioethics law since 1994. The main condition for accessing ART is to suffer from a medical infertility. So far, therefore, women cannot have access to egg freezing in the event that they should wish to be pregnant when they are beyond their physiological limits of age. Nevertheless, the technique is quite easily available in foreign countries, close to France, as for example in Belgium, Spain or England. For some months now, the possibility of legally authorize access to egg-freezing for some so called “social” considerations as age for example, rather than only for medical reasons has been the focus of a heated public debate in our country.

As a CESS, we implemented a research study to further investigate the positions of the people who are the most directly concerned by the technique: i.e. childless women still in reproductive age. We met 36 of them, aged from 25 to 43, for in-depth personal qualitative interviews, to explore what they have to say about the technique, whether or not they might be interested in it for themselves, for which reasons, if the law should be changed, and if so on which arguments.

We will detail the results of the study and discuss them in the light of the ethical principle of Justice, mainly regarding the following issues:

- Should medicine be used to fulfill social expectations?
- Should the regulation be changed and access to the technique be authorized on the ground that reproductive autonomy should be respected and society should not intervene in such a private matter?
- Should society pay for egg-freezing for age-related reasons?

---

## **Restorative Justice and Vulnerability in Medical Malpractice**

Session 2  
Room 5

Susan Fox

St. Anthony Hospital Ethics Committee

Vulnerability is often considered a weakness, but there is more to the picture. It can be a port of entry for compassion, a route for replenishment, and a reason for recognizing the importance of justice. Attention to justice and vulnerability in health care frequently focuses on quality, access and affordability. Justice applies to other aspects as well, however. I propose to focus on justice for vulnerable persons in the context of malpractice and medical error.

Malpractice is a frightening word. Harming a patient through negligence or error violates core values of health care professionals. The assumed victims of malpractice are patients, of course, but medical professionals, too, are compromised. They face jarring professional disruption, immense moral distress, and serious financial

consequences. Sometimes they commit suicide as a result. Naturally, malpractice is frightening to patients as well. They face extreme pain, serious complications, profound changes in self-identity, and steep expense. Sometimes they die as a result. Vulnerability sits on both sides of the table.

To the extent that conventional remedies for malpractice rest on concepts of punishment and retribution, they have a divisive and destructive effect on crucial relationships. Patient and practitioner are no longer partners in a therapeutic alliance: They become adversaries. This is the path of retributive justice.

I submit that there is a more constructive approach through a practice known as restorative justice. It works by re-connecting “offender” and “offended” in a structured process of acknowledging harm and fashioning meaningful redress. It occurs privately, relies on engagement by all parties, and requires a sensitive and skilled facilitator. There are no standard sentencing guidelines or schedules of compensation: Instead, restorative justice is framed by individual circumstances.

Underlying restorative justice there are layers of moral agency, subjective personhood, forgiveness, and the transitive nature of choice. Mining these strata in the present context is not for purposes of extraction but rather illumination. In a sense, we use bioethics to interpret the moral geology of restorative justice. Its landscape among European countries varies greatly. There are – or were – criminal approaches in Germany, schedules of civil compensation in Italy, litigation and money damages in Spain, and a more conciliatory climate in Sweden. Aspects of restorative justice have appeared throughout history. Rituals of apology and atonement and ceremonies of forgiveness in other cultures might provide useful comparative practices.

Each of us is vulnerable in one regard or another. For this reason we share a reason to act justly towards each other. I submit that restorative justice serves those purposes.

---

## **La medicalización de la transexualidad en niños y adolescentes. Aspectos éticos**

Session 4  
Room 7

Sabel Gabaldón Fraile

Hospital Materno-Infantil de Sant Joan de Déu de Barcelona

En la transexualidad, y en la variabilidad de género en niños y adolescentes, se evidencia una relación entre el malestar experimentado y el rechazo social sufrido por las personas con expresiones de género diversas, con la intención clara de que se adecúen a las normas de género vigentes. Este hecho no ha sido tenido en cuenta en la perspectiva médica que ha mantenido actitudes patologizantes. Desde una aproximación ética, se plantea un enfoque despatologizador de la transexualidad y un análisis de las respuestas médicas y sociales, que son más conflictivas en los menores de edad.

La transexualidad sigue formando parte, hoyen día, de las categorías médicas patologizantes que han operado y operan como reguladoras de lo que podemos denominar la “verdad del género”, entendida como un parámetro de normatividad y normalización social que, a través de la exigencia en la concordancia sexo-género y

el establecimiento de la heterosexualidad obligatoria, nos daba una visión específica del mundo.

Desde hace unas décadas, se reconoce que en la configuración de la identidad, ya sea masculina o femenina, intervienen no sólo factores biológicos y genéticos sino elementos simbólicos, psicológicos, sociales, culturales, estrategias de poder, etc., y que son condicionantes muy importantes en la construcción de la identidad personal. En consecuencia hoy, se afirma que las personas no nacemos hechos psicológicamente como hombres o mujeres sino que la constitución de la masculinidad o de la feminidad es resultado de un largo proceso, de una cimentación, que se va fraguando en interacción con el medio familiar, social y cultural.

Si entendemos a los niños y niñas como personas en desarrollo, dependientes de su entorno, con una marcada plasticidad psicológica y donde la identidad de género no es inmutable por lo menos hasta el inicio de la pubertad, es decir no hay garantías de la permanencia hasta la pubertad de sus comportamientos de género no normativos, cabría preguntarnos si ¿es adecuado adoptar medidas rígidas y, en algunos casos irreversibles, contrarias a esta variabilidad al asignarle según sus preferencias un género y un nombre distintos cuando esta situación, en la mayoría de los casos, puede ser reversible?.

Pretendemos psiquiatrizar temas donde la cultura, la sociedad (con sus rechazos e intolerancias), la familia, la historia, etc., tienen un papel predominante para poderlos entender. Realizar un diagnóstico psiquiátrico a personas con identidades y expresiones de género diversas y considerar que su experiencia debe estar necesariamente marcada por un sufrimiento inherente a su condición, tiene el fin de tranquilizar a la sociedad a costa de estigmatizar a estas personas.

---

## **The ethical-psychological aspect of an interaction between transplant surgeons, donors, and society. “Congenital” defect of the development of transplantation [1]**

Farida Maylenova Gabelhakovna

Department of Humanitarian Expertise and Bioethics, The Institute of Philosophy,  
Russian Academy of Sciences, Moscow, Russian Federation.

Session 4  
Room 1

In recent decades, the development of medicine has significantly accelerated due to the increasing use of new technologies. There have appeared opportunities to cure or even prevent many diseases that were previously difficult to cure or not at all curable. 2017 will be the 50th anniversary of the world’s first heart transplant. Now, more than 3 000 heart transplants are performed in more than 330 clinics around the world every year. Considering how complex heart transplantation is, the consequences of it can be most unpredictable. The first patient lived only 18 days after transplant and died from bilateral pneumonia, but now the number of deaths in the first months after the operation has decreased significantly, and people with heart transplant live and 10 and 30 years after the operation. And, in most cases, it is not a heart transplant rejection - the cause of death are infections, injuries, and improper treatment. However, even more effective advancement of transplantation care is prevented by the “congenital” defect of its development - donor deficit.

A huge number of seriously ill people all over the world who could be saved by a heart, kidney, bone marrow transplant, die without waiting for the donor organ that suits them. According to the organization Gift of Life Donor Program, “there are more than 122,000 people in the world awaiting much-needed organs” (including, of course, the heart). According to the website OrganDonor.gov, sad statistics is “22 people die each day waiting for a transplant”, which is not carried out because of a shortage of donor organs, it’s including children.

The solution of these problems is not only in the aspects of medicine. Existing demand in the medical community, and more importantly, in the community of patients, to maintain and increase the donor source, leads to a certain type of pressure on government authorities. It touches on the social mores, values, opinions and views of ordinary people about transplantation. Also in this problem are hidden complex ethical and philosophical issues related to the perception of the human body, its integrity, dignity - including after death.

From the philosophical and ethical point of view, a human can not be a simple functional set of organs and systems. Narrowing the concept of “a human being” to the set of functions of a thinking physiological organism is capable of unleashing threatening practice of using a human body as a set of spare parts.

The report intends to focus specifically on these issues, important not only for development but also for the understanding of the universal meaning of transplantation and organ donation.

---

## **Environment in relation to health, wellbeing and human flourishing: The contribution of 20th century continental philosophy of life and of the subject**

Session 1  
Room 4

Marie Gaille

Health, wellbeing and human flourishing are related in various ways to the emplaced dimension of human existence. In this contribution, we would like to highlight how a network of thinkers that are part of the 20th century continental philosophy gave a specific content to this general and broad idea of a relationship between human health, wellbeing and human flourishing and environment: namely, K. Goldstein, G. Canguilhem and M. Merleau-Ponty. K. Goldstein aimed at determining an appropriate medical approach of brain-injuries. Within this clinical context, he conceived of healthy and pathological states as essentially related to the patient’s environment understood as “the others and the world”. G. Canguilhem focused on the human capacity to tailor one’s milieu of living and conceived of it as the basis of human health. G. Canguilhem’s contribution to the conception of the relationship between health and environment may be indeed considered as crucial. However, the relationship between health, wellbeing and human flourishing must also be thought from the point of view of (individual) experience. M. Merleau-Ponty’s conception of the “lived space” offers key tools to consider this issue. Taking K. Goldstein’s inquiry as a starting point, one may consider how rich is the continental dialogue between him and his French readers G. Canguilhem and M. Merleau-Ponty to conceive of the

relationship between health, wellbeing and human flourishing: their three conceptions are original ones in regard of each other. However, they are deeply connected to each other. They are not necessarily convergent. Nonetheless, they appear as complementary perspectives to think of this relationship. Through the examination of their thought, we will sketch a conception of health that first helps us to fully integrate the environmental component of human health. In order to do so, we will pay attention to the necessary distinctions between the various meanings of the word environment. This conception will also contribute to assess the difference between “health” and “well-being” that is somehow blurred in the WHO definition.

---

## **Balancing care and justice in disability**

Lucia Galvagni

Bruno Kessler Foundation

Session 3  
Room 4

Justice is especially at stake when we consider vulnerability situations and conditions. Among the so-called vulnerable groups, disabled people are one of the most peculiar. The matter of balancing care and justice is relevant and open when we deal with vulnerable people.

In care of disabled people some realities matter. How is it possible to guarantee a good care of disabled people when they arrive at the hospital? Starting from the narrative of a disabled man, who was hospitalised for an acute event and wrote his story of recovery after this experience, the presentation will focus on the necessity to establish good clinical practices in order to host and accompany these persons and to take care of them avoiding forms of discrimination and malpractices and permitting to realise some respectful practices and attitudes towards them and to develop really caring communities.

---

## **Global Health Emergencies, Gender and Vulnerability**

Agomoni Ganguli-Mitra

University of Edinburgh

Session 3  
Room 1

Global health emergencies such as the recent Ebola and Zika outbreaks are often the site of a triad of interventions: humanitarian, care and research. These outbreaks have illustrated how different kinds of health endeavours must co-exist and interact productively in order to develop future prevention and treatment for health emergencies.

At the same time, these health emergencies have been shown to amplify and exacerbate existing inequalities (including structural and global inequalities). As the recent case of Salome Karwah Harris (the Liberian nurse who was at the forefront of the Ebola fight and recently died during childbirth) illustrates, gender injustices can be particularly acute in these conditions, and women, who are already socio-economically marginalised, will be susceptible to bear the burden of further injustice and oppression.

If we look at global health emergencies as liminal spaces, that is, spaces that are neither purely humanitarian, purely health care, nor purely research, we can argue that these spaces require a new approach to ethics, one which reconciles the central values and ethic of these endeavours. On the one hand, these spaces can be considered dangerous spaces, which increase the marginalisation and oppression of women. On the other hand, these spaces can be conceived as sites of opportunity, where a new ethic can learn to be far more aware of gender, structural, epistemic and other kinds of injustices.

In this paper, I use the tools offered by recent feminist theoretical approaches to vulnerability to discuss how the ethics of global health emergencies can learn to be more cognizant of existing injustices and careful of not perpetuating or exacerbating them.

---

## **Withholding and withdrawing treatment, a multicentre study in patients admitted in Internal Medicine wards in the Community of Madrid**

Session 2  
Room 4

Rebeca García Caballero, Diego Real de Asúa, Sergio Gámez, Gala Vega,  
Emanuele Valenti & Benjamín Herreros Ruíz-Valdepeñas

Instituto de bioética Francisco Vallés

**Introduction:** There is little data on withholding and withdrawing treatment (WH/WD) in the Internal Medicine ward. After an initial study, we decided to increase the external validity of our results.

**Objectives:** To describe what are the WH/WD orders in this context and in which patients they are performed.

**Patients and Methods:** We designed a multicenter retrospective descriptive observational study in four hospitals in the Community of Madrid. We included all patients who died in the Internal Medicine ward during 6 months of 2011-2012 and 2012-2013 in each center, without exclusion criteria.

**Results:** A total of 382 deaths were analyzed. The mean age was 85 [±] 10 years. 204 women (53.4%). 222 (58.1%) came from their home. 165 (43.2%) had a moderate / severe degree of dementia and 352 (95.5%) had at least a moderate degree of co-morbidity. The most frequent causes of admission and death were infections and cardiovascular pathology. For 318 (83.7%) were prescribed at least one type of WH/WD. The most frequently prescribed orders were do-not-resuscitate in 292 cases (76.4%, 95% CI: 72.05-80.82), not to perform “aggressive treatment measures” in 113 patients (16.45, 95% CI 13.75 -19,43) and not admission in ICU in 102 cases (14.85%, 95% CI 12.27 to 17.72).

**Conclusions:** WH/WD are widely used measures, the most frequent one being those unspecified such as do-not-resuscitate or not using aggressive treatment measures. The population in which those are employed is elderly and with significant comorbidity and dementia.

---

## Guía de actuación ante la pérdida perinatal en el Parc Sanitari Sant Joan de Deu

Session 4  
Room 7

C. Garcia Terol, B. Carreras Marcos, R. Martin Rodrigo, E. Meleiro Trillo, I. Pérez Pinedo, P. Ricciardeli & E. Reus Calvo

La tasa de mortalidad perinatal está en un 19/1000 mundial, un 4/1000 en la Unión Europea, un 3/1000 en España, y en nuestro centro, una maternidad de aproximadamente 1500 partos anuales, se nos dan estas difíciles situaciones entre 2 y 4 veces al año.

Es un problema, afortunadamente, de minorías, pero es suficientemente importante? Es justo dedicar recursos, ya sean humanos o materiales, a cuidar a estas familias de la mejor manera posible? En el PSSJD consideramos que sí.

La pérdida o muerte de un hijo/bebé es una de las pérdidas más devastadoras que existen y su impacto puede persistir durante bastante tiempo. Es una experiencia única que cada pareja, cada persona, afrontará con su propio estilo y recursos.

Existe la necesidad de conocer el significado de la pérdida perinatal desde la perspectiva de los padres para no caer en posturas paternalistas o en protocolos dogmáticos que consideran iguales a todos los progenitores ante pérdidas a las que ellos atribuyen significados diferentes.

Suelen ser duelos desautorizados u olvidados porque no son públicamente reconocidos ni socialmente expresados, ya que al bebé apenas no lo ha conocido nadie más que los padres; y no en todos los casos. Casi no se puede hablar de ello porque a veces es como si no hubiera habido nacimiento, bautizo o entierro. El niño con frecuencia no tiene nombre, no quedan fotos ni recuerdos de él, ni nada que pudiera avalar su existencia. Por ello surge una sensación de irrealidad.

Cuando el bebé muere intraútero o durante el embarazo los padres, y mucho más aún la madre, tienen que enfrentarse a una situación que nunca se hubieran planteado: parir a un bebé sin vida. En este caso la vida y la muerte caminan juntas. Es una paradoja para la que nadie está preparado y por eso es tan delicado el saber qué decir o hacer.

La experiencia y las demandas de familias que han pasado por este duro trance, nos mostró la necesidad de crear una manera consensuada, respetuosa, multidisciplinar, adecuada a las características de nuestro centro; para dar el apoyo que estas familias necesitan ante un diagnóstico de muerte fetal.

Los objetivos de la guía son individualización de los cuidados, continuidad entre los profesionales que intervienen en el proceso de duelo, circuitos claros y realistas, reconocimiento de la identidad del proceso en sí mismo con un logo propio reconocido por el equipo asistencial, y reconocimiento del feto como un ser social mediante fotografías y/o recuerdos físicos para los padres.

Se ha de procurar también para el equipo de profesionales que interviene en estos casos una adecuada formación y apoyo posterior, estableciendo una comunicación fluida entre todos. Después de cada proceso de muerte perinatal un trabajo de equipo para analizar las acciones, expresar sentimientos y compartir responsabilidades, es beneficioso para el profesional y para la calidad de la asistencia en procesos posteriores.

## **Ethics Experts: still wondering whether they do exist. How are they expected to help in clinical ethical decision-making?**

Session 4  
Room 3

Alessandra Gasparetto

Center for Clinical Ethics, Biotechnologies and Life Sciences Department, Insubria University, Varese, Italy

The issue of expertise in ethics has a very long philosophical tradition, indeed it had already been a matter of debate among ancient Greek thinkers. Nowadays, the question whether experts in ethics do really exist is still receiving much attention because of the increasing involvement in clinical ethics support services of philosophers or theologians highly specialized in moral matters and expected to provide ethics consultation. The notion of expertise when related to ethics is mostly regarded as having both a conceptual side and a strictly practical one. Conceptually speaking it is uncertain whether it exists. If yes, it is in any case dubious whether its existence is also morally acceptable in a democratic society.

As well known, a great deal of efforts has been made by American scholars and practitioners to sketch out the professional profile of the clinical ethicist as well as to define clear procedures to harmonize standards for credentialing and certification of ethics consultants. Nevertheless, even though in most cases an ethics expertise has been acknowledged as the main feature of professional clinical ethicists, it is still an open theoretical question how this expertise is characterized and to which extent should the clinical ethicist be involved in clinical ethical decision-making process which occurs in patient's care.

On the one hand, the equivalence between possessing expertise in ethics and having greater moral knowledge has been largely rejected. Experts in ethics have no moral authority, not even they necessarily possess moral wisdom. In line with these conclusions, the role of the clinical ethicist in clinical ethical decision-making process has been conceived as aimed at clarifying ethical concepts and argumentations, reporting shared ethical standards and consensus views, as well as facilitating agreement among involved parties.

On the other hand, it has been argued that the aforementioned role reveals its inadequacy when the parties involved ask for direct advice or clear indication of the right way to behave in ethically complicated situations. Put it another way, ethics expertise seems to be a loosely defined label attached to the profile of the ethics consultant which still needs to be clarified from a theoretical perspective. It has indeed to be settled whether it deals only with a set of procedural competencies or it is better understood as a normatively oriented task.

Our purpose is to propose a coherent way of intending the role of ethicists who serve on clinical ethics support services. This aim will be pursued by interpreting the notion of ethics expertise both as a procedural means to facilitate moral deliberation and decisions and as a substantial orientation to good ethical outcomes. In relation to this, notions such as practical wisdom and normative expertise will receive new light.

# What is an healing space for Disorders Of Consciousness

Session 3  
Room 2

Charlotte Gilart de Keranflec'h

CNRS-USPC-Paris VII; Faculty of Biology and Medicine, IUHMSP, Lausanne

Consciousness is at the core of neurosciences' and medical's interests. Due to resuscitation progresses and a wider access to rapid hyper medicalized pathways, a new population is emerging: patients severely brain damaged and presenting transitory or permanent Disorders Of Consciousness (DOC). My starting point is a long experience of specialized nursing care with those patients and their families in an acute neurorehabilitation's unit at CHUV, Lausanne, Switzerland. While a spectacular development of research occurred since 1974<sup>1</sup> on this population, paradoxically, our therapeutic supply remains constricted for DOC. We treat them and stimulate them in Intensive Care Unit (ICU) hoping they will emerge from coma. Indeed, until now, neither miracle medication, nor therapeutic tool, nor training has been Evidence Based Proved to recover consciousness.

In this context, and due to the extreme frailty of those patients, caregivers must be both innovating, evidence based cared while still very cautious in their treatments options. Depicted with the fact that specialized clinical scales evaluating coma recovery paid generally little attention to the question of environment as impact factor on consciousness' restoration and evaluation, I started to interest myself to nature oriented-spaces having a rehabilitative potential for DOC at acute stage. I proposed CHUV to create a therapeutic garden especially devoted to DOC' rehabilitation and I started to focus my clinical researches on the impact of Outdoor on coma recovery. First experimental evidence that Nature Assisted Therapies (NAT) can promote relief from acute stress, from mental fatigue, can faster physical recovery from illness and have a long term overall improvement on people's health and well-being exists. Meanwhile, we know that morbidity is related to a "green living environment". Yet, until now, evidence was mainly derived from theories of landscape and environmental psychology and not "enough" from physiological support or quantitative/qualitative data in controlled and/or observational studies which physicians and caregivers need before implementing any NAT.

My reflexion, therefore, emerged out of the need to answer the following questions: what constitutes NAT and their therapeutic value for DOC? Are environmental preference and restoration of consciousness related and, if yes, how? In the present work I'll propose to focus more on physicians and neurorehabilitation staffs 'experiences and theories when providing three Nature Assisted Therapies (NAT): outdoor, therapeutic gardens and hortitherapy to people severely brain damaged including DOC at acute stage<sup>2</sup>. I hope the data collected should be a small contribution but reliable evidence base to support the effectiveness and appropriateness of NAT in DOC treatment choices. The conclusive question will be: if we consider NAT as relevant resource for DOC rehabilitation, what has to be the healing place for fragile patients in a condition of uncertain prognosis? We will try to argue around three axes: historical, epistemological, and political.

<sup>1</sup> When Glasgow Coma Scale was validated: Teasdale G, Jennett B (1974) Assessment of coma and impaired consciousness. A practical scale. *Lancet* 2(7872): 81-4

<sup>2</sup> The work is based on 30 focused and depth interviews with medical and paramedical neuro rehabilitation Suisse and French' staffs.

---

Session 4  
Room 7

## Uso de muestras biológicas y registros clínicos en la investigación. Límites del deber de respeto a la autonomía

María Inés Gómez<sup>1</sup>, Lorna Luco<sup>12</sup> & Patricio Michaud<sup>2</sup>

<sup>1</sup>Centro de Bioética Facultad de Medicina Clínica Alemana – Universidad del Desarrollo, Santiago de Chile; <sup>2</sup>Comité de Ética de Investigación, Servicio de Salud Metropolitano Sur Oriente, Santiago de Chile

Los Comités de Ética se desarrollan en Chile a partir de la década de 1990. Al inicio realizan en forma simultánea la tarea del análisis ético clínico y de la revisión de proyectos de investigación.

En el año 2001, con la elaboración de la Norma Núm. 57 se separan las funciones de los respectivos Comités y éstas hoy están claramente señaladas en lo legislativo y normativo. Actualmente, se han promulgado tres leyes en el país, Ley Núm. 19.628, sobre protección de datos sensibles; Ley Núm. 20.120, sobre investigación científica en seres humanos y la Ley Núm. 20.584 sobre derechos y deberes de las personas en la atención de salud, que cautelan el acceso a la información privada. En estas tres leyes existen artículos que aluden a la privacidad y confidencialidad respecto de la información de atención de salud de las personas y aquella relacionada con la participación de las mismas en proyectos de investigación.

Hoy en día, es posible identificar, a lo largo del país 34 Comités de Ética de la Investigación acreditados y varios en proceso de acreditación y reacreditación. Esta condición asegura que la revisión de las investigaciones, se realice con estandarización de los métodos y procesos que llevan a aprobar o rechazar un estudio.

Este desarrollo, ha traído la necesidad de capacitación de los integrantes y elaboración de normas y protocolos para trabajar a nivel local. Existen permanentemente instancias de reuniones de deliberación entre los miembros de estos Comités y expertos en esta disciplina, de donde surgen para discusión, algunas situaciones que mencionaremos a continuación, aun no resueltas totalmente con la normativa vigente:

1. Uso de placas histológicas y/o muestras de biopsias almacenadas en Laboratorios de Anatomía Patológica.
2. Uso de placas radiológicas con imágenes para ilustrar alguna patología poco frecuente y/o resultados de tratamientos.
3. Uso en investigación de plasma y/o glóbulos rojos descartados en Bancos de Sangre obtenidos de donantes voluntarios para transfusiones sanguíneas.

En el trabajo se muestran argumentos que se utilizan en la deliberación de estas situaciones, homologables a otras que seguirán presentándose aún a casi tres décadas de la implementación de Comités de Ética en Chile. Estas investigaciones generan conflictos en la aplicación de la normativa vigente y, cómo se evidencia en

los ejemplos, enfrentan el deber de respeto a la autonomía de las personas con el beneficio esperado de la investigación planteada.

En el día a día aparecen otros y se hace necesario llegar a consensos que lejos de entorpecer la investigación, hagan que esta sea éticamente posible.

---

## **Problems of social justice in use of biomedical technologies for human enhancement**

Session 2  
Room 2

Elena Grebenshchikova & Boris Yudin

The Institute of Philosophy of the Russian Academy of Sciences, Russia, Moscow

Discussions on the use of biomedical technologies for not only maintaining/improving health but to enhance also some human abilities, capacities and qualities as well allow us to highlight some new facets of the problem of justice in development and application of these technologies. One of the principal differences between these two areas consists in the fact that in the sphere of health problems bioethical discourse is institutionalized for many decades, where as in the field of human enhancement the grounds for evaluating different possible approaches to the use of these technologies in the context of justice up to now are not yet been worked out.

In 2016-2017 we studied opinions of different groups of students and young professionals to the possibilities of human enhancement. 845 young people, including and graduate postgraduate students of medical schools, as well as students in social sciences, humanities and engineering were interviewed. It was the first in Russia comprehensive study of the problems of human enhancement in connection with the ethical issues of innovational developments in biomedicine, social acceptance of new technologies, identification of social and cultural variations in perceiving and acceptance of new technologies.

Among other things we studied some aspects of understanding by respondents problems of social justice in the development and use of advanced medical technologies. The justice for most part was assessed in terms of social accessibility and equity of opportunities. A correlation between an opinion that it is necessary to develop actively new biomedicine technologies, including their use for non-therapeutic purposes, and assessment of acceptability to use psychopharmacological drugs for non-medical reasons. There were not found any socio-cultural differences in relation to the problems of justice between Russian medical students and medical students from Malaysia and India learning in Russia. For example, answers to the question "Is it fair to spend money on projects for the prolongation of human life or it would be better to use them for searching new ways of treatments for diseases?" were distributed equally in the two groups.

One more result of our study shows that the prospective, future-oriented projects (such as, for example, the transfer of consciousness to electronic carriers) for most part are evaluated as rather fantastic and their assessment does not create visible ethical tensions.

Some specific traits were found in relation to the highly competitive areas, where justice rather often was estimated in terms of honesty. The correlations between negative evaluation of doping in sports and use of psychoactive substances in education

for the sake of academic doping were found. At the same time, however, estimates of the psychopharmacological drugs using for improve productivity in learning do not correlate with the estimates of the so-called “smart drugs” in scientific activity. The study was supported by the Russian Science Foundation, project 15-18-30057

---

Session 4  
Room 6

## **Integrated clinical ethics consultation as an educational resource for medical professionals**

Antonia Grigorova<sup>1</sup> & Silviya Aleksandrova-Yankulovska<sup>2</sup>

<sup>1</sup>UMBALSM “N.I.Pirogov”-Sofia,Bulgaria; <sup>2</sup>MU-Pleven,Bulgaria)

Since its introduction as a service clinical ethics consultation (CEC) revealed different benefits for the involved individuals and the institutions as a whole. The organizational perspective focuses on the educational and political functions of CEC. Integrated CEC is viewed as a form and method of building of specific work competence, namely - moral competence. The benefits for the patient result from the changes in the work abilities of medical professionals and in the working environment.

This report is part of a bigger survey which aims at determining needs of improving moral competence of medical professionals through ethics consultation and education at work place.

The specific goal is to study the attitude of medical professionals towards CEC as an instrument for achievement of individual and organizational aims.

Methods. Variety of sociological approaches - observation, interview, document analysis, originally developed self-administered questionnaire. After a pilot study the questionnaire was uploaded in Google forms and the link was e-mailed to different professionals in several health establishments. Altogether 101 respondents took part in the survey of which 75.2% - females, 47.2% - residents of the capital, 43.6% - physicians, 62.5% - above 40 years of age. Statistical analysis was performed through SPSS v.20.0.

Results. Although 38.6% of respondents do not think that medical professionals possess knowledge on medical ethics and law, 33.7% consider such expertise to be useful in moral decision-making towards searching for ‘medical good’ and 28.7% - towards respecting the patient’ interests. Many respondents (35.6%) take undecided position. Special post-graduate programme on clinical ethics is supported by 67.4% of participants and 59.4% would take part in such programme. Decrease in the level of stress as a result of educational programs is expected by 65.4% and decrease in frequency of medical errors in health system by 52.4%. Professional CEC would improve the individual representation of medical professionals and their professional satisfaction according to 30.7% and would have only partial positive effect according to 53.5% of respondents. Improvement of quality of care and patients satisfaction is expected as a result of CEC by 49.5%.

Conclusion. Through appropriate educational forms and methods a supporting organizational environment can be built to promote moral competency of medical professionals. Currently the Bulgarian health system does not have such mechanisms at disposal. CEC has the potential to improve the work atmosphere, to create

ethical climate and eventually “to improve institutional” image. In the context of increased competition between health care providers the positive attitude of medical professionals towards integration of CEC as an educational instrument should be utilized. Earlier studies and experience with METAP methodology demonstrated that bottom-up approaches of CEC are more appropriate in Bulgarian context. Besides the ethical decision-making on a case they provide an opportunity to acquire knowledge and skills. Thus CEC functions as a form of education during the performance of professional tasks. Additionally, ethics discussions can generate new ideas towards the development and the adoption of policies for improvement of quality of care. Hence CEC is positioned in the contemporary concept of organizational learning.

---

## **Emerging Integrative Ethics Support: Experiences with providing continuing ethics support for a treatment team that provides care for transgender persons**

L. A. Hartman & Albert Christiaan Molewijk

Department of Medical Humanities, VU University Medical Centre, EMGO+ (Quality of Care), Amsterdam, The Netherlands

Session 4  
Room 3

Treatment teams involved with transgender persons are often faced with various kinds of moral dilemmas and questions regarding diagnosis and treatment. Since 2013, the department of medical humanities of the VU university medical center (VUMc) provides clinical ethics support (CES) for the treatment staff of the Center of Expertise and Care for Gender Dysphoria (CEGD). We developed several ways of offering and developing CES in close cooperation with the team and the managers of the CEDG. Research both on CES and gender care was and is an important vehicle for joint learning. We specifically aimed at integrating the ethics support within the daily work processes of the treatment teams. In the presentation at EACME we will describe the activities we performed in more detail.

Often, we see CES activities performed as isolated and one-moment activities focusing on an isolated case in which both the ownership and the impact of the CES activities remains unclear. For instance, ethics committees of health care organizations sometimes write guidelines on a clinical topic without actually monitoring the follow-up of the guidelines. Or with regard to moral case deliberation (MCD), there is often insufficient follow up of the moral case (what happened with the insights gained during the MCD, what kind of outcome it brought about).

A common theme throughout all our activities we developed together with the CEDG is that we continuously aimed at integrating the CES-activities within the daily works processes of the CEDG (hence our title: integrative ethics support). There are three ways we consider this project to be integrative ethics support: 1) we specifically aim for the integration of the outcomes of the CES activities within the actual care processes of the CEDG, 2) we develop our CES-activities together with the CEDG, and 3) within our CES activities we integrate CES, research and education. We will conclude the presentation with discussing some challenges of integrative ethics support and presenting some recommendations for a more significant CES.

Session 2  
Room 3

---

## **Future of the freedom to provide crossborder health care services**

Hana Horak & Nada Bodiroga Vukobrat

Health care services form a significant part of freedom to provide services, as confirmed by the ECJ in a number of cases. However, due to their special character and status within the health care policy, it is clear from the outset that they differ from other types of services. Their focus is on the citizen and social benefits (services) provided at national level. Free cross-border provision of health services includes the right of patients to receive health care abroad under the same conditions applicable in their home country. This is especially important, for example, when highly specialized care is needed, which is not available in the patient's home country or in border areas, where the nearest appropriate medical facility is abroad.

The influence of the freedom to provide services in the area of health care also affects other freedoms and different specific areas such as freedom of movement of workers and members of their families and social rights in connection therewith and the worker's demand for health care benefits from other Member State. As with all cross-border services, the co-ordination of laws through different procedures, including the open methods of co-ordination, plays a particularly important role in the field of health services as well.

Internationalization and globalization, free flow of capital, improved workers' mobility and entrepreneurship have raised new issues regarding cross-border provision of health services and competition. There are two types of questions that should be answered. One is the question of boundaries to which health care insurers are ready to open to the market and the other group of questions includes physicians' freedom to provide services, freedom of recipients from other Member States, free movement of pharmaceuticals and medical-technical appliances and cross-border competition of private providers of healthcare insurance.

---

Session 3  
Room 5

## **“Why Should I Question a Patient’s Wish?” A Comparative Study on Physicians’ Perspectives on Their Duties to Respect Advance Directives**

Ruth Horn

The Ethox Centre, University of Oxford

This article explores factors that impede the implementation of advance directives to refuse treatment (ADs) in three European countries: England, Germany and France. Taking into account socio-cultural and legal aspects, the article shows the extent, to which the law can, and does, influence physicians' decisions to implement ADs. The findings presented are based on qualitative interviews exploring physicians' sense of duty to respect ADs and the reasons given for failing to implement the law. It will be argued that this depends on: 1) how strictly the legal status of

ADs is defined, and 2) whether the law actually addresses the reasons why physicians may hesitate to implement ADs (e.g. uncertainty about validity, importance of patient preferences).

The article emphasises the importance of doctor-patient communication and shows how the implementation of ADs could be improved by making discussions about treatment preferences a legal requirement.

---

## **Proposta d'un nou fonament de la vulnerabilitat**

Session 1  
Room 6

Marc Illa Mestre

Universitat de Barcelona

**Objectius:** presentar la importància de la casa com un element fonamental dins de les ciències de la salut. La reflexió pretén estudiar la importància d'aquesta tant en un sentit teòric (filosòfic) com pràctic (a través de diversos fenòmens representatius: sensellarisme, violència domèstica, violència de gènere).

Alhora, la reflexió servirà com a argument per palesar la insuficiència i rigidesa del mètode principalístic de Beauchamp i Childress a l'hora de resoldre casos concrets.

**Metodologia:** per demostrar que la casa i tot el que aquesta recull (intimitat, funcionalitat en la vida quotidiana, desplegament de la identitat...) té una importància capital en les ciències de la salut, es presentaran les següents reflexions: en primer lloc, s'atendrà a les característiques de la vulnerabilitat (tant en un sentit genèric com mèdico-sanitari) per acabar conclouent que el "no ser a casa" mentre "s'és a l'hospital" pot suposar una nova causa de la vulnerabilitat del pacient (entesa en un sentit holístic, no merament físic); per entendre degudament què és i representa la casa, es prendrà com a referent el llibre "La resistència íntima" de J. M. Esquirol, en el qual es descriu la importància d'aquesta en la vida quotidiana; alhora s'extreuran alguns conceptes proposats per H. T. Engelhardt.

La reflexió s'articularà mitjançant l'aplicació i estudi de categories com "intimitat", "respecte", "funcionalitat en la vida quotidiana", "estrany moral" o "hospitalitat", aquesta última com a proposta ètica davant de la controvèrsia presentada.

**Resultats i conclusions:** la reflexió conclourà posant de manifest que la casa és un element fonamental a l'hora de parlar de vulnerabilitat, de bioètica i de ciències de la salut. S'arribarà a aquesta conclusió mitjançant dues vies argumentals: 1) la filosòfica, prenent com a fonament l'associació casa-intimitat; pèrdua de casa-pèrdua d'intimitat i 2) la pràctica, a través de fenòmens socials (sensellarisme, violència domèstica...) i fets significatius com les altes voluntàries que destaquen la rellevància de la casa com a punt neuràlgic en la reflexió bioètica.

---

## **“Growth itself is the only moral end” . The relevance of Dewey’s moral theory for continuous ethics education of healthcare professionals**

Giulia Inguaggiato<sup>1</sup>, Suzanne Metselaar<sup>1</sup>, Rouven Porz<sup>2</sup> & Guy Widdershoven<sup>1</sup>

<sup>1</sup>Department of Medical Humanities, EMGO+ Institute for Health and care Research, VU University medical centre (VUmc), Amsterdam The Netherlands; <sup>2</sup>Clinical Ethics

In this paper we will elaborate on the relevance of Dewey’s theory of education and morality for continuous ethics education of health care professionals. According to Dewey, “the good” means: aiming at the best. This means that “growth itself is the only moral ‘end’” (Dewey, J. 1957. *Reconstruction in Philosophy*. Boston: Beacon Press. p. 177), and therefore that moral learning should not be regarded as looking for definite answers to moral questions, but as a continuous process of adaptation through which moral agents refine and improve their moral competences by confronting them time and again with the specific inputs that come from their daily life’s experience.

Our paper addresses the significance of Dewey’s approach in the context of a pragmatist perspective on clinical ethics support thereby investigating whether Dewey’s theories of education and morality can 1) provide useful insights for the practice of CES by focusing on its educational aspects, and 2) redefine the role of the clinical ethicist in today’s pluralistic society.

In the wake of Dewey we will argue that instead of aiming to reach recommendations or action guiding judgments, clinical ethicists should foster an inter-subjective learning process aiming at the continuous amelioration of the moral competences of the caregivers involved in the deliberation. What really matters is not the achievement of an ultimate goal, but the process of improvement and “moral growth”. According to Dewey thinking that the acquisition of precepts, valid once and for all, leads to moral maturity implies (on the contrary) condemning humanity to a perpetual state of moral immaturity. Therefore clinical ethics support should be intended as a continuing educational process through which healthcare professionals learn how to address the specific ethical problems that need to be solved in a critically constructive and contextually sensitive way.

Consequently we claim that the clinical ethicist should play an active the role in promoting moral growth of health care professionals. We argue that redefining the professional role of the clinical ethicist as someone who fosters “normative professionalism” (Kunneman) in professionals is all the more important in today’s multicultural and pluralistic health care context. In fact in a society characterized by ethical diversity and multiculturalism, clinical ethicists cannot fall back on a shared moral framework to be applied to certain situations. As a consequence, instead of focusing on justifying choices on the basis of fixed and general assumptions clinical ethicist should train health care professionals to become skilled in revising habits, rules and laws in light of circumstances by engaging in a shared process of moral inquiry.

## To Fix or Not to Fix, the Cosmetic Labiaplasty Question

Session 4  
Room 1

Eghoihunu Ireo

North Lincolnshire and Goole NHS Foundation Trust

**Introduction:** A Private Patient attended my NHS ward for Labiaplasty. Cosmetic labiaplasty, first described in 1984, is surgery to alter healthy external female genitalia, for non-medical reasons. The quantity in the private sector is not captured in official statistics. **Objectives:** To assist with labiaplasty, explore the Consultant's views and challenge my own. Ask whether it is ethical to offer cosmetic labiaplasty and use the four principles of medical ethics to guide discourse.

**Discussion:** Choice for cosmetic labiaplasty may be swayed by numerous limitations and controlling interferences that taint meaningful autonomy. Non-maleficence challenges relevant specialties to regulate training and assess efficacy of procedures with well-designed prospective studies with long-term follow-up. Depression and suicide are significantly higher in the population choosing cosmetic surgery therefore perioperative care should involve psychologists. Surgeons are reminded to manage the often-narrow expectations of cosmetic patients to achieve beneficence. Justice of offering cosmetic labiaplasty depends on perceptions of healthcare, as a social asset or free-market commodity. The Female Genital Mutilation Act (2003) makes 'cutting' illegal in the UK or upon UK citizens at any age. I compare cosmetic labiaplasty with this practice and review the law.

**Conclusion:** The harms of offering cosmetic labiaplasty extend beyond risks of surgery, to mental illness, promotion of concerning cultural views and social vulnerability of women. After applying these principles, I conclude that performing cosmetic labiaplasty is not entirely ethical nor is it always unethical. Thus, it is the surgeon's burden to develop their practice conscientiously, accountable to a supervising body.

---

## The assessment of capacity: Challenges faced by Swiss Clinicians

Session 3  
Room 3

Luzia Iseli<sup>1</sup>, Helena Hermann<sup>2</sup>, Manuel Trachsel<sup>2</sup>, Tenzin Wangmo<sup>1</sup> & Bernice S. Elger<sup>1</sup>

<sup>1</sup>University of Basel; <sup>2</sup>University of Zürich

**Background.** Decision-making capacity (DMC) is an important concept in patient-oriented medicine since it is a prerequisite for valid informed consent to any medical treatment. It underscores the much valued rights of an individual, that is, the right to self-determination. Although there are many empirical studies on DMC and on its theoretical background worldwide, little is known about its actual implementation in daily practice of healthcare practitioners. This study as part of the nationally funded project on DMC aims to explore the challenges faced by the Swiss Clinicians when confronted with the situation necessitating assessment of DMC.

**Method.** The data from this study comes from a nationally funded study on DMC and its assessment using a new tool (UUKit) developed by the project applicants. To improve the UUKit face-to-face interviews were carried out with a

purposive sample 24 healthcare professionals from Switzerland. The participants were mostly physicians (n=18), one psychologist, and five nurses. During the interview, the professionals were asked about their practice, difficulties, and experience with DMC. The interviews were recorded, transcribed verbatim, and analyzed thematically using a qualitative inductive-coding approach. In this paper, we analyzed the information concerning DMC which were not directly related to the UUKit.

**Results.** The study participants reported facing different challenges in the assessment of DMC and in most cases participant stated that they would not make DMC assessment unless they have to. The challenges were related to difficulties posed by patient's health condition and situations that the physician felt unprepared or uncomfortable making a DMC assessment. They reported that certain patient characteristics posed difficulties not only in making decision concerning the presence or absence of capacity but also posed additional questions related to risk of that decision for the patients. These patient characteristics included presence of dementia, fluctuating condition, and psychological illness. From the part of physicians, they found it challenging when their opinions conflicted with that of the patient and/or other colleagues. They were in addition concerned about the consequences of this decision and did not feel fully prepared to do so. Related to this point of consequences was when they had to make DMC assessment in the context of legal issues and when they knew of other interests of the relatives. In some cases, all these factors came together to bring about an even challenging situation.

**Conclusions.** Although DMC is extensively discussed in theoretical literature, daily work implementation is far from being trivial. The assessment is a difficult process which depends on many factors and interests. Data from this qualitative examination present the need for further work to address these challenges of DMC. With the demographic changes that are expected, it is likely that more and more such assessments must be carried out. Thus there is need for continued education for DMC assessment to become a normal part of the medical profession.

---

## **Which outcomes of Moral Case Deliberation do participants perceive as important and which do they experience? – Insights from the field study with the Euro-MCD Instrument**

Session 4  
Room 4

J. C. de Snoo-Trimp, M. Svantesson-Sandberg, Albert Christiaan Molewijk, H. C. W. de Vet, Guy Widdershoven, B. S. Brinchmann & G. Ursin

Context: Moral Case Deliberation (MCD), a form of Clinical Ethics Support, is implemented in an increasing number and various types of healthcare settings throughout Europe. Yet, still little is known about important and experienced outcomes according to MCD participants. Therefore, an instrument was developed to measure these two aspects of MCD outcomes: the Euro-MCD Instrument\*. Recently, a field study has been conducted in Sweden, Norway and the Netherlands in order to a) study both important as well as experienced outcomes and to b) revise the instrument. In total, more than 700 healthcare professionals completed

the questionnaires before and/or after MCD participation. The findings provide valuable insights for further refinement of the instrument.

**Objectives:** To obtain key insights for a refinement of the Euro-MCD Instrument, a field study was performed. The main aim was to examine the factor structure of the instrument, including its stability before and after MCD participation. A second aim was to describe the responses to the Instrument and compare participating countries, healthcare domains and professions.

**Methodology:** The Euro-MCD Instrument consists of a questionnaire distributed before (Section A) and a questionnaire distributed after (Section B) participation in MCD. Both sections include 26 possible outcomes of MCD of which the importance has to be rated on a 1-4 Likert scale. Section B further asks to state for each possible outcome if and to what extent the outcome is actually experienced, both during the MCD sessions as well as in daily practice. The 26 outcomes are covered by 6 domains: Moral Attitude, Moral Reflexivity, Emotional Support, Collaboration, Concrete Results and the Organizational Level. Answers were analyzed using SPSS (Statistical Package for the Social Sciences), version 22. The stability of the factor structure was tested with Exploratory Factor Analysis.

**Results:** Preliminary factor analyses for ‘perceived importance’ revealed that 17 out of 26 outcomes constructed a factor structure of 3 domains that was stable for T.0 and T.1. Preliminary factor analyses for ‘experienced outcomes’ provided a different factor structure. Final results, including ratings for importance and experience, will be presented at the conference.

**Discussion:** The findings provide the basis for revision of the Euro-MCD Instrument. The factor analyses show how outcomes might be allocated to various domains. The ratings of importance and experience feed discussions about the relevance and clarity of MCD outcomes. Consequences for deletion and reformulations require further theoretical and normative thinking. As the refined version of the Euro-MCD is still in the development phase, we would like to discuss suggestions for deletion of items and reformulation of domains with the audience of the EACME Conference.

\*Svantesson, M., Karlsson, J., Boitte, P., Schildman, J., Dauwerse, L., Widdershoven, G., Pedersen R., Huisman M. & Molewijk, B. (2014). Outcomes of Moral Case Deliberation-the development of an evaluation instrument for clinical ethics support (the Euro-MCD). *BMC Medical Ethics*, 15(1), 30.

## CRISPR/CAS9: Patent war for controlling the book of life in the era of Bioprecariousness

Sonia Jimeno

University of Barcelona

The present research is focused on the problem of social inequalities in health, in particular, on the confrontation between the right to property specified in Article 17 of the Universal Declaration of Human Rights (intellectual property rights, patents) and the right to health specified in Article 25 (public, global health).

The root of such confrontation is due to the monopoly granted by a patent to the owner thereof during 20 years of exploitation, given that a patent is a property right granted by the Government of a country to an inventor to exclude others from making, using, offering for sale, or selling the invention in exchange for public disclosure. This monopoly granted, mainly, to big companies (especially to pharmaceutical and biotechnological companies) is protected by the TRIPS Agreement (Agreement on Trade-Related Aspects of Intellectual Property Rights) of the World Trade Organization and it is especially controversial in the so-called "patents of life" which allow to have control over life by patenting genes, seeds or drugs).

One of the most controversial cases of "patents of life" is the current patent war on the cutting-edge genome editing technology CRISPR/Cas9, which is also known as the "molecular scissors". This new "pair of scissors" may be used to cut the two strands of DNA at specific sites, in order to repair, delete, replace or add parts to a DNA sequence to cure genetic diseases. This scientific breakthrough has triggered a bitter dispute over the IP rights of this technology between the University of California, Berkeley and the Broad Institute of Harvard on the grounds of "patent interference".

This patent battle over CRISPR shows the impact of this cutting-edge technique, which may be used in a wide range of fields, such as:

- Reproduction: editing genes in human embryos;
- Crops and livestock: increasing yield, introducing resistance to disease and pests;
- Industrial biotechnology: developing "third generation biofuels" and producing chemicals, materials and pharmaceuticals;
- Biomedicine: pharmaceutical development, xenotransplantation, gene and cell-based therapies, control of insect-borne diseases; and the most important one: Curing genetic diseases.

However, the possible "side effects" both at a scientific and ethical level are still unknown. As the sociologists Ulrich Beck states we are living in the risk society and CRISPR-Cas9 could be one of them.

What is really clear is that this "molecular scissors" will not be available for the whole population, as it happens already with the lack of access to essential drugs of a great deal of the population affected by neglected diseases, such as AIDS or malaria.

Thus, the question at this point is "Who owns science?" and more important, "Why are so many people living in an era of bioprecariousness while science is

opening up new ways of editing the book of life?” Bioethics must give an answer to these crucial questions and must, of course, not get out of the way of science.

---

## **Factors that challenge and facilitate research integrity: a qualitative study of researchers and advisors in the UK**

Session 4  
Room 5

Mari-Rose Kennedy & Ruud ter Meulen  
University of Bristol

Research misconduct is a growing global concern in scientific research with potentially serious consequences. Thus, research integrity is important to prevent misconduct undermining public trust and damaging scientific endeavour. Bad science wastes funds and produces spurious findings that can also be detrimental to public health. Blatant cases of Falsification, Fabrication and Plagiarism (FFP) are rare, but these are thought to be the tip of the iceberg. More subtle and insidious problems stemming from questionable research practices or ‘sloppy science’ are believed to be far more wide spread and underreported.

An increasingly competitive research culture has been criticised for contributing to work environments that do not promote research integrity. Here, competition for research grants or jobs can fuel a ‘publish or perish’ approach to research. This arguably leads to some researchers, at worst, committing large scale misconduct such as FFP, or cutting corners in their work. Exactly what constitutes research misconduct and how cases are dealt with is debatable and varies internationally. One approach is to increase regulatory measures to punish perpetrators and deter others from wrongdoing. However, an alternative is to promote research integrity as part of the research culture, rather than relying on top-down enforcement alone.

In order to refine research culture to promote research integrity, it is important to better understand the issues by exploring the context. There is limited research from a European perspective exploring what researchers and, the people who work to advise and support them on governance and integrity issues, think about research integrity and misconduct. This presentation will report on the findings from a series of focus groups conducted in the UK with researchers and advice staff. This work is part of a wider task involving researchers from Norway, Italy and Estonia, to explore perspectives from the ‘work floor’. In particular, factors highlighted by researcher and advisors as being a challenge to or facilitating research integrity will be discussed. The research is part of a wider project PRINTEGER: Promoting Integrity as an Integral Dimension of Excellence in Research. The project goals are to develop tools and educational materials to enhance research integrity. This is part of an ongoing effort to promote a research culture where research integrity is part and parcel of what it is to do research, not just an external and restrictive control system.

---

Session 4  
Room 2

## **Healthcare professionalism at times of austerity**

Angeliki Kerasidou & Patricia Kingori

The Ethox Centre, Nuffield Department of Population Health, University of Oxford

Greece is one of the European countries most severely affected by the 2008 global economic crisis, and its healthcare system is among the national institutions most shaped by its effects.

In this paper, we draw data from a qualitative study conducted in Greece in 2014, which examined austerity-driven changes in the healthcare system through in-depth interviews with 20 healthcare professionals. Doctors, nurses in five different location in mainland Greece were interviewed on their perceptions of austerity and how ideas of professionalism are challenged by it. Participants reported working conditions characterised by dramatic increases in public hospital admissions alongside decreases in personnel, consumables, materials, and also many hospital closures. Many drew on analogies of war and fighting to describe the effects of healthcare reforms on their working lives and professional conduct. Despite accounts of deteriorating conditions and numerous challenges, healthcare professionals presented themselves as making every effort to meet patients' needs, while battling to resist guidelines which they perceived diminished their roles to production-line operatives. We will close by reflecting on the effects austerity might have on notions of professionalism, and the ability to provide competent and empathetic care.

Session 2  
Room 4

---

## **The mother of invention – how policy makers use necessity argumentations in health care coverage decision practice**

Tineke Kleinhout-Vliek, Antoinette de Bont & Bert Boer

Institute for Health Policy and Management, Erasmus University Rotterdam, the Netherlands

Context – Policy makers use several criteria, such as (cost-) effectiveness and budget impact, in health care coverage decisions. They also assess the necessity of coverage by taking into account both the need of the individual patient and the greater good of society. The argumentation shape these oft-conflicting values take and the way in which they are used varies considerably, especially for the societal categorisation.

Aim – To investigate the role of policy makers in health care coverage decisions and the way they use argumentations in valuing the perceived necessity of coverage.

Methods – We utilise observations and audio recordings of decision-making processes (15 hours), interviews with policy makers (10) and document analysis (8) to describe the decision making process in four coverage decisions in the Dutch context: an orphan drug, maternity care, front teeth replacement therapy and paracetamol-vitamin preparations.

Results – Both the individual and the societal necessity categories are frequently used by policy makers, but every decision process has a surprisingly idiosyncratic shape. The need of the individual patient is always highly valued in coverage decisions. The use of the societal necessity category is much more variable. The policy

makers are influential in this process; they are highly capable, pragmatic, keen to experiment and quick to adapt in inherently difficult and strained professional settings. They are creative in their use of argumentations and they utilise their professional networks successfully. In this way, they impact coverage decision making practice greatly.

Conclusions – Health care coverage decisions do not follow a set pattern in terms of argumentations used; the way the need of the individual patient and the greater good are weighed varies per decision. The policy makers and their professional network enable this valuation process.

---

## Care and Justice in the Hospital Arena

Session 2  
Room 3

H. Kohlen<sup>1</sup> & A. A. M. van Nistelrooij<sup>2</sup>

<sup>1</sup>Philosophical-Theological University, Vallendar, Germany; <sup>2</sup>University of Humanistic Studies, Utrecht, The Netherlands

Field studies in clinical ethics from Germany and Norway (Kohlen 2009; Halvorsen et al. 2009) revealed that physicians and nurses distribute their caring time of being attentive to patients in a manner that puts questions of justice and responsibility to the forefront. Moreover, patients and their relatives were given different amounts of time to speak up for their interests. The findings provoked a discussion on understanding justice not as an abstract ideal, but as a matter of care practices in the every-day world of physicians and nurses. We have been bringing into consideration the objections made by care advocates against theories of justice in a social and health care arena (e.g. Van Nistelrooij 2015). We argue that justice can best be conceptualized from a care ethical perspective that accounts for the social realities of medical and nursing practices in the hospital arena. In order to discuss justice from a care ethical perspective we decided to focus on approaches that have systematically analysed the meaning of vulnerability in asymmetrical relationships (Kittay 2011) and make questions of responsibility an important matter of clarification (Walker 1998, Young 2011).

Halvorsen, K./ Forde, R./ Nortvedt, P. (2009): The principle of justice in patient priorities in the intensive care unit: the role of significant other. *Journal of Medical Ethics*, 35: 483-487.

Kittay EF. (2011): 'The Ethics of Care, Dependence, and Disability', *Ratio Juris* Vol 24, No 1, March.

Kohlen, H. (2009): *Conflicts of Care. Hospital Ethics Committees in the US and in Germany*. New York/Frankfurt.

Van Nistelrooij I. (2015): *Sacrifice. A care ethical reappraisal of sacrifice and self-sacrifice*. Leuven.

Walker, M.U. (1998): *Moral Understandings. A Feminist Study in Ethics*, New York.

Young, I.M. (2011): *Responsibility for Justice*. Oxford/ New York.

---

## **Has moral case deliberation impact on the degree of moral sensitivity on employees in (forensic) psychiatric care?**

Swanny Kremer, Duco Kroon, Albert Christiaan Molewijk & Marinus Spreen

**Introduction.** Clinical Ethics Support Services (CESS) are likely to contribute to the moral sensitivity of the participating health care professionals. However, there is still a gap in knowledge in measuring moral sensitivity empirically within CESS contexts, in particular when offering moral case deliberation (MCD). This paper is part of a larger PhD study concerning the implementation and evaluation of moral case deliberations in a maximum-secured forensic psychiatric hospital.

**Research questions.** 1) To what extent can moral sensitivity of staff members (i.e. sociotherapists) be measured? 2) Does the moral sensitivity of employees grow when they participate in MCD's on a regular bases?

**Design.** We applied a cross-sectional design. Three groups of respondents were defined. Group I did not participate in any MCD. The other two groups were scheduled to have eight MCD's of which group II had no facilitator (unstructured group) and group III a certificated facilitator (structured group). All groups were followed a year. The Revised Moral Sensitivity Questionnaire (MSQ-R) (Lütznén et al., 2006) was used to measure moral sensitivity. The MSQ-R consists of a positive and a negative dimension of moral sensitivity. The positive dimension of moral sensitivity expresses moral responsibility and moral strength (5 items). Moral stress represents the negative dimension of moral sensitivity (4 items) (Huang et al., 2015). The MSQ-R's were completed by 80 sociotherapists working in 9 divisions one time at the end of the study period.

**Results.** Controlling for gender, education, age, work stress, work experience, and dissemination of knowledge some significant differences were found between the three groups. Sociotherapists participating in structured MCD's were more morally sensitive in the positive dimension compared to those who didn't participate in any MCD. However, sociotherapists participating in structured MCD's were not more morally sensitive in the positive dimension compared to sociotherapists that participated in unstructured MCD's. Finally, work stress seems to have a negative, medium to strong influence on the positive dimension of moral sensitivity. Regardless whether sociotherapists participate or not in MCD, sociotherapists experiencing more stress at work are less morally sensitive compared to those experiencing less stress at work. For the negative dimension of moral sensitivity, no significant results were found.

**Discussion.** This pilot study tries to gain insight into the relation of improving moral sensitivity by moral case deliberation and how to measure it. The results of this pilot study can be used in future studies on moral sensitivity within the context of MCD and CESS. A restriction of this study is the cross-sectional design. In future studies moral sensitivity perhaps can be better measured by repeated measurements to gain better insights in changes over time. Furthermore, future research should pay attention to the actual meaning of improved moral sensitivity in daily practice.

## **A developing country's socioeconomic perspective of informed consent in clinical practice**

Session 4  
Room 6

Brenda Kubheka  
University of Witwatersrand

Informed consent protects the moral and legal rights of the patients whilst guiding clinical practice. It is not just an ethico-legal tool but it also fulfills the clinical, and administrative roles.

In developing countries, vulnerable patients face constraining situations affecting voluntariness thus threatening the theoretical ideal of informed consent. These constraints include challenges arising from low literacy levels, socioeconomic status, and historical experiences, to name a few. Vulnerable societies tend to be served by practitioners who do not speak the local language and sometimes, do not understand or acknowledge local cultural beliefs. These challenges are compounded by the use of *ad hoc* interpretation services threatening the rights of patients due to interpretation errors, threat to confidentiality and the impact of interpretation services on the patient-practitioner relationship. Therefore, there is a need to harmonize local and Western ideals when facilitating informed consent in order to bridge the gap between theory and practice of informed consent.

This paper seeks to explore elements of valid informed consent within the context of socioeconomic issues confronting patients from developing countries and the importance of bringing such issues to the practitioners' attention.

---

## **Neurodegenerative diseases and global and/or specialized care : practices and discourses**

Session 3  
Room 6

Mathilde Lancelot & Agathe Camus  
Université Paris Diderot, France

We propose to examine and to question some ambiguous discourses<sup>1</sup> about “global patient care” and/or “specialized patient care” in the context of neurodegenerative diseases (ND). Indeed, guidelines<sup>2</sup> about ND (type Parkinson and Alzheimer diseases) promote the notion of global care understood as a somatic, psychic and environmental multidisciplinary evaluation and follow up for patients. However, the notion seems to be used in a decontextualized and unquestioned way. Practices show that these pathologies require specialized and hyperspecialized care. But is this type of care concretely compatible with a global follow up?

This reflection inscribes itself into a largest thinking about how to medically and non-medically support persons with neurodegenerative diseases in hospital care context.

First of all, it seems necessary to question the historical meaning of the notions of “global care” and “specialized care”; what it implies and what it highlights in practices. How the notion of “global care” can be distinguished of the notion of “patient-centered-care” ? In addition, it is important to see how global and specialized or hyperspecialized care<sup>3</sup> are articulated in practice. Second of all, fieldworks

and observations permit us to highlight a patient claim about “a lack of accompagnement.” But what are we talking about when we talk about “accompagnement”<sup>4</sup>? Does that notion, emerging from the patient’s discourses, correspond to the idea of “global care”?

Thus, we propose to construct an epistemological and philosophical reflection about medical specialization, global care and “accompagnement” on the basis of our field observations focused on two specific care situations : Parkinson’s patient and Alzheimer’s patient, both confronted to non curative care and treatments. Indeed, these two kinds of neurodegenerative diseases require simultaneously non and hyper specialized care. In order to illustrate this point, we will consider two specific situations : deep brain stimulation on Parkinson’s patient (hyper specialized care) and care for Alzheimer’s patient in internal medicine hospital services (patients with Alzheimer disease are cared in such services for intercurrent disease and comorbidity and non specifically for Alzheimer disease). These two cases both illustrate the complex articulation between hyper specialized, non specialized and global care. Therefore, we have chosen to present them as complementary reflexions and work on it as a pair.

<sup>1</sup> Guidelines, medical literature, physicians speeches etc.

<sup>2</sup> HAS Recommandations “Maladie d’Alzheimer et maladies apparentées : prise en charge des troubles du comportement perturbateurs”, Mai 2009 & HAS Guide du parcours de soin “maladie de Parkinson”, Septembre 2016. <http://www.has-sante.fr>

<sup>3</sup> By exemple : deep brain stimulation in Parkinson’s disease.

<sup>4</sup> See Gaille M., Horn R., The role of “accompagnement” in the end-of-life debate in France : from solidarity to autonomy, 2016.

Session 3  
Room 6

---

## **Sharing Care Responsibilities between Professionals and Families in Mental Healthcare. A Plea for Inclusion**

Elleke Landeweer

Center for Medical Ethics, Institute of Health & Society, Faculty of Medicine, University of Oslo

Since the eighties, major changes have been made in the organization and focus of professional mental healthcare. Influenced by the need to become more cost-efficient, in combination with an increasing context of individualization in society, the care locus shifted from institutions to communities. Mental health services deinstitutionalized: The number of hospital beds reduced and community and home-based services developed. At the same time, visions regarding how to care for persons with mental illness changed. New moral orientations developed, focusing on coping and recovery for individuals with mental illness, rather than containment and taking control of the patient within institutions. It was assumed that persons with mental illness would thrive from living in ‘normal’ communities, being able to develop a personal identity beyond being a patient. Correspondingly, the shift from care in hospitals to the community created new expectations regarding the division of care responsibilities, between persons in need of mental health care, their personal

networks and professional care providers, and caused a grown reliance on informal care from personal networks. Although the shift to community care has resulted in a higher quality of life to persons with mental illness, families frequently reported they felt forced into taking up more care responsibilities.

In this presentation we will look into the question how a fair division of care responsibilities can be realized when it comes to fine-tuning care responsibilities between informal and professional carers. First, we will discuss how the transition in mental healthcare changed the allocation of care responsibilities between personal networks, persons with mental illness and professional caregivers and if it caused an unfair burden of care responsibilities for personal networks. We will investigate why informal care provided by personal networks was taken for granted in these processes; why it was assumed they would fill the gap of care responsibilities when professionals changed their targets and argue that it placed personal networks in a vulnerable position. Second, the moral relationship and its theoretical assumptions between professionals and personal networks will be further explored to explain 1) the moral drivers of professionals for not considering the interests of personal networks in policy changes as well as 2) the moral nature of personal networks for taking up care responsibilities without a fight. The differences will be highlighted to illustrate the complexities between fine-tuning between informal and professional care. From that, we will discuss if families should be included in policy changes and present a pathway to family inclusion that could foster a more just division of care responsibilities serving both the individual with mental illness as well as their personal networks.

The research leading to these results has received funding from the European Union Seventh Framework Programme (FP7-PEOPLE-2013-COFUND) under grant agreement no 609020- Scientia Fellows.

---

## **Enjeux pédagogiques de la culture palliative: quel apprentissage social de l'accompagnement de la fin de vie?**

Rozenn Le Berre & Grégory Aiguier

Centre d'Ethique Médicale, Institut Catholique de Lille

Session 2  
Room 6

Contexte. Les textes officiels et recommandations de bonnes pratiques au niveau international comme national, à l'exemple de la loi Leonetti-Claeys du 2 février 2016 dans le contexte français, attribuent une fonction pédagogique à la démarche palliative. L'objectif de cette diffusion de la démarche palliative étant de mettre en œuvre une forme d'apprentissage social de la fin de vie. Ainsi, les équipes mobiles de soins palliatifs, par exemple, ont tout à la fois un rôle de conseil, d'expertise, de formation et d'accompagnement dans la mise en œuvre de la démarche palliative. Ces différentes finalités interrogent les fondements et pratiques pédagogiques de la démarche palliative, et ce, en regard des finalités parfois différentes des dispositifs de formation continue. En effet, apporter un soutien aux équipes, diffuser et/ou faire émerger une certaine philosophie du soin, ou encore favoriser le développement de compétences techniques, relationnelles, voire émotionnelles, renvoient à des orientations pédagogiques fort différentes. On peut y voir à la fois une démarche assimilée

à la maïeutique, lorsqu'il s'agit de faire émerger une culture et une philosophie du soin au sein des équipes, et une démarche davantage comportementaliste visant une régulation et une standardisation des pratiques lorsqu'il s'agit d'apporter une expertise aux équipes.

Problème. Dès lors, quel modèle pédagogique peut-on mobiliser pour fonder la fonction pédagogique inhérente à la démarche palliative et tenir ensemble toutes les finalités fixées ? Pour beaucoup, la pédagogie par compétences, aujourd'hui largement privilégiée dans les curriculums en santé (Parent et Jouquan, 2013), constitue une voie pertinente. L'objectif de cette communication est d'en questionner les fondements théoriques ainsi que l'ingénierie pédagogique (les méthodes, les postures, les dispositifs) qu'elle présuppose, que ce soit sur les terrains du soin ou de la formation. Par là même, nous verrons en quoi cette réflexion proprement pédagogique questionne les enjeux d'une (re)définition des soins palliatifs dans le contexte contemporain.

Méthode. Nous traiterons cette problématique à partir d'une revue de la littérature sur le sujet mais aussi d'une relecture pédagogique des pratiques palliatives, telle que nous les observons dans le cadre d'un projet de recherche consacré à la pédagogie des soins palliatifs.

Résultats et discussion. Nos premières observations et réflexions nous amènent à beaucoup de prudence par rapport à un modèle qui tend parfois à objectiver la démarche palliative (référentialisation des compétences, etc.) au risque d'en faire une spécialité. Selon nous, l'équilibre à trouver entre les dimensions objective et subjective de la démarche palliative appelle plutôt le développement d'une pédagogie du sujet et d'un apprentissage social des soins palliatifs dont nous esquisserons les grandes lignes.

---

## Réflexion éthique et soins palliatifs : la perspective des éthiques du care

Session 2  
Room 6

Rozenn Le Berre

Centre d'Ethique Médicale, Institut Catholique de Lille

But et contexte. Dès ses origines, la réflexion éthique semble être inhérente à la démarche et à la culture palliative, et ce, en interrogeant la nature du soin médical, ses limites, son sens. En mettant en avant, comme véritable enjeu médical, que le soin à l'humain ne se réduit ni à l'objectivité du corps ni à la finalité de sa guérison, et en insistant sur ce que le soin à une souffrance globale, psychologique, sociale et spirituelle, a de fondamentalement soignant, les soins palliatifs rejoignent et mettent à jour une dimension éthique et philosophique. Les éthiques du care, courant récent visant à proposer une approche nouvelle de l'éthique, constitue alors un courant à explorer. En effet, la notion de vulnérabilité, qui y est centrale, est interrogée à l'épreuve d'une réflexion sur le travail : quels sont les ressorts moraux du travail de soin, pour les personnes soignées comme pour les soignants, en ce que ce travail nous confronte à une vulnérabilité potentielle partagée ?

Problème. Notre objectif sera donc d'interroger les fondements épistémologiques de la culture palliative et ce, afin de les mettre en dialogue avec le courant des

éthiques du care : en quoi les soins palliatifs sont éthiques ? Les soins palliatifs sont-ils naturellement “ancrés” dans le care ? En quoi les éthiques du care viennent questionner les fondements et pratiques des soins palliatifs ?

Méthodes. Pour ce faire, différentes disciplines (sociologie, philosophie, psychologie du travail) seront mobilisées afin d’enrichir une perspective philosophique à portée critique visant à interroger les finalités, les conditions ainsi que le sens donné au soin. Le contexte propre aux soins palliatifs interroge les éthiques du care, dans leurs fondements comme dans leur diversité.

Discussion et perspectives. En interrogeant les conditions, les finalités et les fondements des soins palliatifs, et ce, dans leur contexte d’exercice quotidien, l’enjeu est de proposer des pistes de réflexion tendant à interroger et renouveler la dimension éthique propre aux soins palliatifs : comment cette réflexion éthique au cœur du soin se confronte à des enjeux contextuels et pratiques propres à ce qui fait le soin au quotidien ? Le soin à la vulnérabilité des personnes en fin de vie se confronte à celle des soignants, au cœur d’un “travail du care” (Molinier, 2013).

#### Bibliographie

Molinier Pascale, *Le travail du care*, Paris, La Dispute, 2013.

Molinier P., Laugier S., Paperman P., *Qu’est-ce que le care ? Souci des autres, sensibilité, responsabilité*, Paris, Payot, 2009.

Garrau M., Le Goff Alice, *Care, justice et dépendance ; introduction aux théories du care*, Paris, PUF, 2010.

Gilligan C., Hochschild A., Tronto J., *Contre l’indifférence des privilégiés ; à quoi sert le care*, Paris, Payot, 2013.

---

## **Between palliative care and euthanasia: doing justice to the most vulnerable**

Carlo Leget

University of Humanistic Studies, Utrecht, The Netherlands

Session 3  
Room 2

In most countries of Europe end-of-life care is dominated by a palliative care approach which is characterised by multidisciplinary care for patient and family in order to realize the best possible quality of life, excluding the option of active termination of life. While palliative care is developed and defined from the perspective of care-givers, in many European countries more and more a radical patient-centeredness is advocated according to which the option for active termination of life is explicitly strived for. Palliative care on the one hand, and physician-assisted-dying on the other, are seen as alternatives placing health care professionals in opposite of patients. Putting it in terms of principlism, well-being is placed in opposition to respect for autonomy. Even in countries like the Netherlands and Belgium, where euthanasia has been legalized for 15 years, euthanasia is often framed as a practice which is more respectful of autonomy (and subjective dignity) than palliative care.

In our view this opposition is a false one, based on a too simplistic view on autonomy, a naïve view on the social and political context of discussions and doing no justice to the most vulnerable person involved: the dying patient. What is needed is an approach that transcends the false dichotomy of care giver and care receiver,

offering a more realistic account of autonomy and suffering in which vulnerability and the importance of social relations are valued. A new art of dying – helping to deal with autonomy, suffering, relations, guilt and hope – could offer a framework in which patients, proxies and caregivers could search for the best possible way to deal with human vulnerability and mortality. Such an art of dying could incorporate much from palliative care and would be open to the possibility of active termination of life. Most important, however, would be the quality of the process of interaction preceding the end of life.

Session 3  
Room 5

---

## **Influence of an ACP intervention on documentation of end-of-life issues – a cluster randomized clinical trial**

Trygve Johannes Lereim Sævareid<sup>1</sup>, Lisbeth Thoresen<sup>2</sup>, Reidun Førde<sup>1</sup> & Lillian Lillemoen<sup>1</sup>

<sup>1</sup>Centre for Medical Ethics - University of Oslo; <sup>2</sup>Department of Health Sciences - University of Oslo

**Background.** Approximately 50% of Norwegians die in nursing homes. When an end of life decision has to be made, many patients no longer are able to contribute to the decision-making process. Next of kin are usually not aware of patient's preferences on end-of-life issues in Norway. In order to strengthen respect for patient autonomy, patients should be invited to participate in an Advance care planning (ACP) conversation while they still are capable of communicating preferences. For patient preferences to be of value, they must be readily available documented in the electronic health record (EHR).

**Methods.** This study is a cluster randomized clinical trial in Norwegian nursing homes. Nursing home wards were pair-matched on certain criteria. One ward from each pair was then randomized to the intervention group. The intervention was systematic implementation of an ACP conversation guideline. Documentation in the EHR was registered, at baseline and after a 12-month intervention period. Both alive and dead patients were included for registration, and events from the last year leading up to either death or the registration date were registered. Registrations included documentation of conversations with patients on end-of-life treatment, patient hopes and worries for the future, information and participation wishes, and preferences for life-prolonging treatment and hospitalization. Data will be analyzed using a mixed models regression model in SPSS.

**Results.** 8 nursing home wards from 8 nursing homes participated. A total of 317 patient EHRs were included. Data will be analyzed by the time of the presentation at the conference. Preliminary findings suggest that conversations with patients on end-of-life treatment are more often documented as is assessment of competency to consent after implementation of ACP. Documented wishes on life-prolonging treatment and hospitalization suggest a reduced focus on next of kin wishes, and more focus on patient wishes. Documentation of end-of-life issues became more readily available in the EHR.

**Discussion/conclusion.** Systematic implementation of ACP seems to strengthen patient autonomy at the end-of-life in nursing homes. Readily available documentation is an instrumental foundation for decision-making based on the patients' wishes

and preferences. By not involving an advance directive as part of the intervention the documented preferences may be less clear. However, this lack of standardization may have contributed to increased possibility for patients to elicit what is important to them in end-of-life care.

---

## **Implementing advance care planning (ACP) in Norwegian nursing homes; a process of knowledge translation.**

Lillian Lillemoen

Centre for Medical Ethics, University of Oslo

Session 3  
Room 5

**Background.** Advance care planning (ACP) is internationally renowned as a good strategy for ensuring better care and participation in decision-making at the end of life for nursing home (NH) residents. Although ACP is not legally binding in Norway national guidelines recommend taking into consideration the resident's preferences when it comes to decisions about life-prolonging treatment. Still the majority of Norwegian NH's do not have routines in place to ensure this. As part of a larger research project, in the period from April 2015 to August 2016, we conducted an intervention project aiming to implement ACP in Norwegian NH. The aim of this paper is to describe how the implementation was received and illuminate lessons learned.

**Methods.** Training in end-of-life conversations, implementation of a guideline for ACP, supervision of NH-personnel, information meetings and materials (posters and letters to residents and next of kin) were key elements of the implementation. A local project group consisting of one NH manager, one NH doctor and one educational nurse (the coordinator) was appointed for each NH. The local project groups were followed throughout the process with regular meetings in which they shared experiences with ACP implementation. Data is based on tape-recorded verbatim transcribed discussions from these meetings, a total of 160 pages, in addition to 13 written notes from the coordinators aiming at their experiences with the implementation.

**Results.** Despite committed coordinators and support to the project from NH-management we found the implementation challenging. For most nursing home staff, ACP was something the coordinators were doing; it was none of their business. Organizational instability; busy days with little opportunity for preparations, sick leaves resulting in high turn-over for nurses and doctors, are all factors resulting in resistance against new routines offering ACP to all patients.

**Discussion/Conclusions.** Confidence and transparency between all actors involved in a project are essential for a successful implementation. Included in this is a climate where critical questions about the interventions and the implementation process are welcomed. We have learned that although agreeing on the aims of an intervention study NH-staff and researchers have different understandings of what it means to participate in a research project. Implementing ACP in NHs implies translating knowledge from one context to another. The lessons learned from this implementation process should be used in future implementation of new ACP practices.

---

## Mejorando el acceso al tratamiento anticoagulante como parámetro de justicia en la atención de pacientes con enfermedad cardiovascular

Lorna Luco<sup>1 2</sup>, María Inés Gómez<sup>1 2</sup> & Carmen Astete<sup>1</sup>

<sup>1</sup>Centro de Bioética Facultad de Medicina Clínica Alemana-Universidad del Desarrollo, Santiago de Chile; <sup>2</sup>Hospital Padre Hurtado, Región Metropolitana, Santiago de Chile

El siglo XXI nos pone, a nivel global frente a una demanda creciente de atención de población con diagnósticos de Enfermedades Crónicas No Transmisibles (ECNT), frecuentemente afectada por más de una patología y con compromiso multiorgánico. Se define la ECNT como aquella de larga duración, progresión lenta y cuyo fin no puede preverse o no ocurrirá.

En la atención de salud, prevalece actualmente, el modelo orientado a la atención del cuadro agudo, siendo éste insuficiente para las ECNT. Se observa además que es frecuente que los médicos restrinjan su actuar a un área específica, poniendo el foco sólo en la enfermedad o en el órgano afectado. Se atiende de acuerdo a la estructura organizacional de la institución, en desmedro, de una atención integral de los pacientes.

Hoy día, la alta prevalencia de enfermedad cardiovascular en la población adulta, hace que el Tratamiento Anticoagulante conocido con la sigla TACO sea de alta demanda. Hemos observado una población de aproximadamente 1980 personas que se controlan en el Nivel Secundario del sector público de salud por esta causa, pertenecientes a comunidades de alta vulnerabilidad social. Acuden a control cada 30-35 días, para recibir su tratamiento.

Estos pacientes tienen indicación de TACO en forma transitoria o permanente, de acuerdo al protocolo de tratamiento de las distintas enfermedades lo que da por resultado alrededor de 25.000 controles cada año.

El proceso de atención implementado implica que los pacientes deban permanecer varias horas en cada control en el centro de atención. Se genera en ellos desgaste físico, gastos en traslado y esperas prolongadas. En pos de mejorar este escenario, se plantea una estrategia de atención que busca mejorar el acceso y la oportunidad del tratamiento llevando la toma de muestra y entrega de los medicamentos a la Atención Primaria, manteniendo en el Nivel Secundario el monitoreo clínico y el manejo sólo de los casos clínicamente más complejos.

Al tratar de avanzar en la puesta en marcha de esta medida, se evidencian barreras de tipo organizacional, administrativa y territorial que dilatan el inicio de la implementación, manteniendo inequidades, influyendo en la calidad de atención y por ende en la calidad de vida de las personas. Esto significa un desafío a los gestores en su responsabilidad de ofrecer una atención de salud digna.

En el trabajo a continuación se analizan estas barreras y se relacionan con los principios de la Bioética y los Fines de la medicina que se deben vincular de manera permanente al quehacer de las instituciones de salud.

Concluimos que se debe comprometer a los profesionales de los distintos niveles de atención con el valor de la importancia de la buena coordinación, integración, coherencia y el deber ético de poner al paciente al centro de la atención para lograr los mejores resultados con el tratamiento indicado.

---

## Beyond gift-giving: transplantations, agent identity, and sharing

Session 2  
Room 1

Pawel Luków  
University of Warsaw

The imagery of gift-giving has remained the foundation of transplantation ethics since the first successful organ transplantations. Despite invoking such moral ideals as selflessness, caring, and solidarity, this imagery also suggests that human body or its parts are transferable objects which are controlled by persons. Accordingly, human body or its parts can be objects of rights akin to property rights or rights in things. However, the imagery may encourage, although indirectly, normative proposals (such as regulated markets in transplant organs), which run the risks of objectification, commodification, and commercialisation of the human body or its parts. It will be argued in the presentation that in order to conceptually block such normative proposals the imagery of gift-giving should be abandoned in favour of a view based on the imagery of sharing in a misfortune. This imagery is also more consistent with the ethical presuppositions of public health care systems.

The argument will have two parts. Firstly, it will be shown that the conceptualisation of the relation of a human agent to their body as analogous to the relationship of a person to a transferable object is anthropologically and experientially inadequate. The normative view of the relation between a person and their body as that between an owner (or quasi-owner) and an owned object is therefore mistaken. Secondly, it will be proposed to view the relation between a person and their body as that of identity or partial identity. On this account, persons are their living bodies, even though it could be argued that they are more than that.

This approach allows for a change of the normative view of organ donation, retrieval, and transfer in at least three respects. First, it requires that a decision about one's own body be viewed as an exercise of a personal right, which is neither identical with nor reducible to a property-like right in a thing. Second, since, on this view, such a decision can be made only by a living individual, transfer of a body part from one person to another can be legitimate after securing that person's explicit informed consent, whereas post mortem retrieval of bodily material does not require such consent. Third, the view proposed redefines donation as an act of responding to another person's misfortune by sharing in this misfortune. A body part, which is used in transplantation, is a vehicle of caring, mutual support, and solidarity, on which public health care systems are founded.

---

## La qualité de la vie, qu'est ce que cela signifie aujourd'hui ? / Quality of Life: what does it mean today ?

Milena Maglio

En 1971, le philosophe Daniel Callahan, fondateur du Hastings Center intitulait sa contribution au volume *That they may live* : “La Qualité de la vie : qu'est ce que cela signifie ?”. Il critiquait la position exprimée, un an plus tôt, par un éditorial du *California Medicine*. Ce dernier proposait que la qualité de la vie devienne “Une nouvelle éthique pour la médecine et la société”. Sur le fond, Callahan était d'accord avec les auteurs de l'éditorial pour estimer que la capacité de la médecine à préserver la vie (biologique) avait conduit les médecins à se poser la question de la qualité de la vie qu'ils étaient en train de préserver.”. Il considérait pourtant dangereux, à partir du concept de qualité de la vie (concept dont la signification demeurait insaisissable, changeante et soumise à des interprétations particulières), de prendre des décisions relatives à la vie et à la mort. Cela pouvait entraîner des discriminations. Le principe de justice était donc en péril. Afin d'éviter cette dérive, il paraissait nécessaire d'associer la qualité de la vie aussi bien à des critères objectifs (besoins physiques nécessaires à la survie) qu'à des critères subjectifs (préférences individuelles).

Aujourd'hui, quarante années plus tard, on s'accorde à considérer la qualité de la vie comme un objectif du soin. Malgré ce consensus, sa signification n'est pas plus saisissable qu'autrefois. Des pratiques, des valeurs et des principes opposés peuvent être justifiés en son nom. La recherche actuelle de critères toujours plus objectifs, scientifiques et mesurables de la qualité de la vie risque de laisser peu de place à une sphère de décisions subjectives. La question posée par Callahan se relève, aujourd'hui, toujours pertinente. Mais comment relever le défi théorique qu'elle nous lance ?

---

## Justice and Vulnerability in Childcare

Júlia Martín Badia

Pediatricians and ethicists are increasingly recognizing the necessity of promoting minors' autonomy in decisions regarding their health. But this is not free from problems. Some of these difficulties are rooted in the way justice and vulnerability are understood and managed in this field.

According to Jürgen Habermas, justice can be defined as the conflict-solving process that takes into account the perspectives of everyone affected. This can be extrapolated to the healthcare field in terms of the decision-making process that takes into account the views of everyone involved. Consequently, justice should be understood as minors' equal opportunity of participating, together with parents and clinicians, in medical decisions referred to them. At the same time, justice should be understood as equal exercise of rights and duties, so that the decisions made are both effective and efficacious. In this sense, clinicians, parents and minors have specific roles inside the healthcare relationship, but all of them aimed at

finding a happy medium (according to Aristotle's definition of justice) between paternalism and adultism (assuming greater responsibilities than those for which one is prepared). This happy medium will never be arithmetic nor the same for every minor.

But this decision-making process is asymmetric (the healthcare relationship is asymmetric), because minors are vulnerable. In fact, they are doubly vulnerable: because they are minors and because they are ill. Furthermore, vulnerability can be understood as a condition, as a situation and as a susceptibility and minors may fall in all three cases. What is important is perceiving it, not as a weakness, but as an opportunity for personal growth and for autonomy acquisition.

Ultimately, as minors are vulnerable, their autonomy should be promoted by means of a concept of justice, whose central rights and duties are the minors' right-duty of developing self-caring capacities, the minors' right of being taken care of (by parents as well as clinicians) and the minors' right of taking care of (the ones who care for them, the available healthcare resources. . .).

These notions of justice and vulnerability are closely related with others, such as dignity or solidarity, which are also key elements of autonomy promoting in minors. According to Immanuel Kant, dignity is the intrinsic value of every person. Minors should be allowed to take part in healthcare decisions that affect themselves, in equal opportunities, because although they do not have full autonomy, they do have dignity. That is why parents as well as clinicians should make a gesture of solidarity (understanding it as responsibility) and respond to minors' wish for autonomy by transforming the medical consultation into a space where they can express their vital narrative. That is what supporting minors in their process of developing self-care capacities consists in.

Our proposal is to delve into all these elements that concern the role justice and vulnerability play in decision-making processes involving children. We will as well exemplify these concepts in two frequent and problematic cases: drug use and health problems related to parent's divorce.

---

## **Goodness Versus Fairness in Public Health Decision Making: Designing an Animated Bioethics Learning Module**

Session 2  
Room 4

Hannah McLane & Nate Totushek  
University of Pennsylvania

**Objective.** In this project, we created an online animated bioethics learning module to be administered to healthcare workers, medical students, and future public health workers. Our aim was to improve critical thinking about distributive justice issues, including identifying the 'winners' and 'losers' of different decisions and evaluating the fairness of these choices. We aimed to make this learning module a free-standing learning tool, as well as one that could be used to prepare students for a lecture about this topic.

**Background.** When medical resources are limited, as they often are, prioritization decisions must take into account many different issues. Often the 'outcome-efficiency orientation' of conventional economic analysis is used, which may not

provide a complete picture of all pertinent issues. John Broome describes a potential issue that may arise as a choice between “fairness versus doing the most good.” The implications of prioritizing “goodness” over “fairness”, however, may not be immediately evident to individuals making these choices, and may in fact contradict their personal value systems.

**Methods.** We chose to base this learning module around a central thought experiment written by Daniel Wikler. This scenario is as follows: “You are a chief of a ward with 100 patients. 50 of these patients need 2 pills to survive. One pill does not help them. 50 of these patients need 1 pill to survive. You have only 50 pills. What would you do?” We discussed with Daniel Wikler common responses to these scenarios, as he has been teaching about this topic for many years at the Harvard School of Public Health. We then used a Google form and embedded the animation and relevant questions into it, to capture the thought-process of the respondent. After the module is over, there is a post-test in which the respondent revisits the original 50 pills questions and is asked to justify their answer.

**Results.** We successfully created an animated tool and questions in a Google form for assessing critical thinking ability. The 50 Pills Module takes 20-30 minutes to complete. We have administered to tool to several medical residents and Public Health students. Responses were encouraging; many stated that they had never considered these aspects of decision making and felt they learned form the tool. Formal results from this tool are pending.

**Conclusions.** We created an online learning module to present a distributive justice decision making in an interactive way. So far we have received positive reviews by medical residents who have completed this learning module. We believe animated teaching tools can help bring decision-making reasoning exercises to life and help students and participants better understand the relevance of this kind of reasoning.

---

## **Determinants of New and Emerging Labour Risks in the Workplace : Health and Safety Practice in Spain**

Session 1  
Room 4

Teodor Mellen<sup>1</sup> & Helena Roig<sup>2</sup>

<sup>1</sup>University of Barcelona; <sup>2</sup>Institut Borja de Bioètica-Universitat Ramon Llull

In the whole EU national and European legislation it is established how safety and health in the workplace should be managed. However, the way the law is applied in practice is not the same in all businesses and in all EU countries under common legislation. Particular differences are shown in terms of environment and cultural and social frameworks, in which companies operate with different specified regulatory frameworks, traditions and industrial relations and social protection systems, safety and health infrastructure support in the work and the very different economic and employment climate.

This paper examines the differences in the application of occupational safety and health practices in Spain and identifies the contextual determinants of these practices resulting, on the one hand, from the historical evolution and current national

regulatory frameworks for safety and health at work, and the current contexts of the labour market and health and safety, on the other.

In addition to traditional occupational risks (TR), industrial processes may generate other risks described by the European Agency for Safety and Health at Work (EU-OSHA) as “New and Emerging Risks” (NER). The basic definition of NER is “any occupational risk that is new or increasing”, according to several studies carried out by the EU-OSHA in which all the aforementioned risks, both general and specific, are identified and analysed. Consequently, the main purpose of this study is to investigate the explanatory mechanisms that link the determinants of risk management and how these organizational problems explain the performance of risk control by companies.

The analysis of this work is based on the second European Survey of Companies on New and Emerging Risks (ESENER-2), which is a large-scale multinational survey of organizations conducted by the EU OSHA. It covers 36 European countries—EU member states (EU-28)—plus Albania, Iceland, Macedonia (FYROM), Montenegro, Norway, Serbia, Switzerland and Turkey. The aim of the survey is to collect information on how health and safety are organized in workplaces across Europe.

The results obtained for Spain case come from a selection of the sample made from territorial criteria from a  $N = 3162$ , with a sample error of  $\pm 1,77\%$  for a confidence level of 95.5% where  $P=Q$ . The sampling unit and the statistical or analysis unit is the “work center” or local unit instead of companies. Based in a multivariate statistical treatment complemented with the modelling of structural equations analysis, the paper shows how the improvement in security management practices reduces the New and Emerging labour Risks. These results provide an important clue about the future of public policy formulation in this area and highlight the importance of safe management of New and Emerging labour Risks.

---

## **The Intersection of Hospice Care and Family Dynamics: What happens when End of Life Care and Child Care Collide?**

Maximiliano Mendieta

University of Michigan at Flint UM Institute for Healthcare Policy and Innovation at  
Ann Arbor

Session 3  
Room 3

This study looks at the labor choices and consequences families face when the need to provide care for their children and their own aging parents arises simultaneously. The literature in child care and decision-making is well established, while the end-of-life care literature is primarily focused on the biopsychosocial nature of hospice care.

The independent phases of child care and end-of-life care have not been studied before as part of a single continuum and both offer an opportunity to explore the challenges and opportunities that exist for society, researchers, policy makers, and families. This research topic lends itself to a retrospective analysis of the values embedded in child care and end of life care policies hence offering opportunities to advocate for family, health, and economic policies driven by values that work in

unison rather than in conflict. The alignment of values can yield better quality of life for the family and the aging parents, policy innovation, and sustainable economic growth.

The research question is: how does understanding the decision making process in child care inform the decision making at the end-of-life care? By understanding how government policy drives childcare and by proxy end-of-life care decisions, we can better evaluate the outcomes of such policies and determine if these policies are delivering the desired outcomes.

This research comes at a time when fiscal deficits and economic stagnation dominate the political agenda, which is likely to translate into program cuts and service reduction. Not taking into consideration how the policy in place affects the family can have undesirable economic consequences for households as well as the economy overall. More importantly, it can undermine the core values of the family unit, self-determination at the end-of-life, and government policy.

---

## **The use of Restraint in dementia patients: can we include it in a care project?**

Session 3  
Room 4

Elena Montaguti<sup>1</sup> & Federico Nicoli<sup>2</sup>

<sup>1</sup>Center for Clinical Ethics Biotechnology and Life Sciences Department Insubria University, Varese, Italy; <sup>2</sup>Clinical Ethics Service, "Domus Salutis" Clinic, Teresa Camplani Foundation Brescia, Italy

**Context.** We intend to analyze the use of restraint in dementia patients focusing mainly on the ethical aspects connected to this practice. The aging of population reveals a growing increase of dementia, which affects social relations, behaviors, emotions, functioning, memory, orientation, speech and thought of the people affected (World Health Organization, 2007). Dementia patients often end up in institutional care with a possible risk of restraint practices. The wide use of restraints in nursing homes is directed particularly to patients with poor mobility, high dependency or dementia and is also due by organizational characteristics, such as the lack of nursing staff. Nowadays, these people are cut off from society and live alone in long-term care. **Objectives:** Can restraint be considered as a therapeutic treatment or should it be regarded as a humiliating practice comparable to torture if it reduces unjustifiably the patient's freedom? Only if we assume restraint as a therapeutic treatment we have to establish the criteria that consent to justify this practice.

**Methodology.** To achieve our objective we need first of all a general overview of the use of restraint and of its legal criteria. On the basis of this concept we will then focus on the possibility of employing restraint in care project. We will focus on three different types of restraint (physical, chemical, environmental) explaining the ethical problems arising from them: the problem of consent and the use of restraint not for the patient's well-being but for the needs of the caregivers (physical); the dilemma between the use of a drug for the patient's treatment and its use simply to control the patient's behavior (chemical); the problem of who is entitled to decide and the loss of rights (environmental). The use of physical restraint raise particularly ethical and legal aspects: on the one hand, the control of the behavior of others leads to

psychological traumas with negative outcomes; on the other hand, there is no ethical and legal reason to restrict the freedom of others. It should not be forgotten also the role of the legal guardian (the patient's relatives or a judicial authority if the patient has no relatives) in the use of restraint considering the psychological implications that the choice of restraint involves.

Results. Many authors properly analyze the problem of restraint in dementia patients by focusing on the ethical aspects of this practice, e.g. the respect of the patient's autonomy and wellness and the risk/benefit assessment. Although few authors seem to consider the possibility of drafting guidelines for this practice, many of them define the guidelines for the use of restraint.

Discussion. This study intends to explore whether restraint is rightful, to detect the conditions that may justify it ensuring the best interest of patients and to consider the possibility of planning care by including the potential use of restraint.

---

## **Implicaciones éticas de la telemedicina en el control remoto de dispositivos cardíacos implantables**

Session 4  
Room 7

María José Ruiz Montilla, Joan Costa Mateu, María Tornel Cerezo & Anna Baiget Pons

Las múltiples utilidades de la tecnología informática en nuestro día a día, es un tema bien conocido. Redes sociales, TIC, robótica nos acompañan en todo momento, en nuestra vida. Una de las aplicaciones con más futuro en relación a la asistencia sanitaria, es la Telemedicina. A distancia podemos controlar, diagnosticar, evaluar, y hacer seguimientos de pacientes que por diversas características no pueden desplazarse al centro de salud. Muchas son las ventajas de este nuevo sistema de ejercer la medicina: facilitar el control y la monitorización de pacientes complejos, facilitar el acceso a las tecnologías, realizar una atención integral de todo el proceso, fomentar la igualdad de oportunidades para los distintos tratamientos, integración de programas de calidad y mejora continua, etc. Todo ello con el objetivo de mejorar la atención a nuestros pacientes y ofrecer una atención de calidad que se adapte a las nuevas tecnologías existentes.

El caso particular que nos ocupa serían los dispositivos cardíacos implantables: marcapasos (MCP) y desfibriladores internos (DAI).

Las posibilidades que otorgan estas nuevas tecnologías a la hora de tratar a pacientes complejos portadores de dispositivos cardíacos son múltiples. Desde control del funcionamiento interno del dispositivo, hasta la detección de anomalías en el ritmo cardíaco del paciente. Datos que sin el control remoto no podríamos conocer ni valorar ni poder hacer seguimiento y en el caso necesario, tratamiento del mismo.

Es importante y necesaria la labor que realizan los profesionales sanitarios a la hora de controlar a estos pacientes sin que acudan al centro sanitario.

Pero, el conocimiento de la normativa ética y jurídica para el tratamiento de estos pacientes con telemedicina en muchos casos no está tan claro. Muchas son las normas legales que hacen referencia a la confidencialidad de los datos de un paciente plasmados en una historia clínica, tanto de forma tradicional mediante papel, como de la forma más actual, con soporte informático. También los profesionales deben

conocen la reglamentación que se ocupa de proteger el Principio de Autonomía, siendo el consentimiento informado de obligado cumplimiento para la realización de cualquier actuación sanitaria.

El objetivo de la presente comunicación es aportar conocimiento sobre las implicaciones éticas que comporta el manejo de la tecnología de control remoto en dispositivos cardíacos implantables, con el fin de ofrecer tanto a nuestros pacientes como al propio personal una herramienta de aprendizaje que garantice la asistencia de calidad y el cumplimiento tanto de la normativa legal como el cumplimiento de la normativa ética.

Session 4  
Room 6

---

## **The limit of doctor professionalism to support patient decision making**

Akira Nakazawa

The purpose of this paper is to examine the role of doctor professionalism in patients' decision making process. In this paper, decision making process does not mean formulating health policies of the nation but determining each patient's choice of treatment. Regardless of its diversity, most of the definitions of doctor professionalism contain the factor of doctor-patient relationship, for example maintaining patients' trust or respecting for patients' welfare. It is said that doctors' efforts to maintain the medical knowledge and to explain the content of treatment honestly are needed in order to gaining patients' trust. However, such efforts are not enough for a patient to determine his choice of treatment. Because patients' view of life is valued in the decision making process, it is insufficient for a doctor to support his patient only by knowledge and skills of medical profession. To support patient decision making, it is needed to understand a patient's life situation and guess a patient's way of thinking. This indicates that perspective of medical profession is not sufficient to support patient decision making. In the process, insight is needed to guess patient's feelings and sensitivity is also needed to perceive patient's emotion. Such ability is not developed by medical science, but literature or art. In medical education, perspectives other than medical profession have not been much focused on. It might be due to that the primary aim of medical education is training students as a medical profession. Similarly, doctors also seldom have opportunity to learn a new perspective other than medicine. It is problematic that doctors regard the knowledge and skills of medical profession as perfect tools to support patient decision making.

Through exploring the limit of professionalism in the aspect of supporting patient decision making, this paper is shedding light on the basis of doctor professionalism.

---

## Necessity of Scientific Tribunals: Scientific Regulation of Medicine in Context of Philosophy

Session 4  
Room 4

Eva Neu<sup>1</sup>, Michael Ch. Michailov<sup>1</sup>, Christoph Lütge<sup>1 2</sup>, Tatjana Senn<sup>1</sup>, Ursula Welscher<sup>1</sup>, Ralf K. Stappen<sup>1 2</sup>, Albert Oswald<sup>1</sup>, Heike Wankel<sup>1</sup>, Michael Schratz<sup>1 3</sup>, Rumen Stainov<sup>1 4</sup> & Germain Weber<sup>1 5</sup>

<sup>1</sup> Inst. Umweltmedizin (IUM) c/o ICSD/IAS e.V. POB 340316, 80100 Muenchen, Germany (Int. Council Sci. Develop./Int. Acad. Sci. Berlin-Innsbruck-Muenchen-NewDelhi-Paris-Sofia-Vienna); <sup>2</sup>Inst. Ethics (Dir.), Techn. Univ. Muenchen, Muenchen, Germany; <sup>3</sup>SP Group, Kipfenberg, Germany; <sup>4</sup>School Educ. (Dean), Univ. Innsbruck, Innsbruck, Austria; <sup>5</sup> Univ. Fulda, Univ. Sofia, Univ. Boston (upto 2005), Fulda, Germany <sup>6</sup> Fac. Psychol. (Dean), Univ. Lxbg&Vienna, Vienna, Austria

Introduction. Enormous progress in research by scientific revolutions (Thomas Kuhn) after Copernicus is related to misuse of science causing disastrous repercussions typified by global health-medical and educational problems, ecological destruction, chemical-physical pollution, treat of atomic war, etc. Evidently present juridical and political systems cannot stop self destruction of humanity. Foundation of scientific tribunals – from local up to international – can support scientific incl. health-medical regulation in form of independent link between legal and political institutions. Medical philosophy, esp. ethics could play a leading role in this matter.

Conception. Medical philosophy considers interaction between humans-groups-institutions by epistemology (incl. scientific theory)-ethics-aesthetics. Policy and law regulate the science, protection of human health incl. medicine, but this is evidently insufficient: Enormous global problems need new strategies. Creation of adjuvant juridical and scientific bodies could help not only for solution of conflict situations, but also initiate new approaches conc. better health-medical science. Some examples:

A. Research: a. H.von Helmholtz (physician/physicist) defamed many years the also eminent scientist J.R.Mayer (discovery: conservation-energy-law). b. German Helmholtz-Centre-München (past GSF) deposited illegal radioactive material (biggest European atom-scandal acc. to the present German Vice-Chancellor S.Gabriel), leading to danger of water contamination. Government did not prove this matter! c. Scandal about HIV-virus-discovery: L.Montagnier received Nobelprice, but not R.Gallo, by immorality! d. Austrian & German universities destructed international bio-medical laboratories of the international Institute for Eco-Medicine (IUM) by totalitarian methods.

B. Education: a. German medical-faculty declined dissertation (6-positive/2-negative-referees) without giving text-argumentation (dangerous ideology). b. Caused by doubtful plagiarism doctor-degrees of German politicians are dispossessed incl. after 33 years: e.g. Prof. Annette Schavan/Ex-Minister of Science, Ambassador of Vatican-City; but government did not give order for enquiries to prove moral & scientific qualification of professors and other dissertations!

C. Technology-Chronobiology & photobiology: European-Union gave order for a. summer-winter-time (difference) leading to permanent patho-physiological-reactions

supporting diseases, b. replacement of physiologically-conform light-bulbs by dangerous energy saving lamps (pathogenic light-discontinuity-spectrum and possible mercury-intoxication).

D. Clinical Medicine. a. Monodimensional (ultra-specialization) immorality and economy in medicine damages patients and state, e.g. a patient/medical doctor was pharmacological and surgical treated for 10 days – costs about 15000 Euro. The same disease after 1 year false oligodimensional, ultra-specialized treatment led to invalid state (patient cannot go) with costs about 0.7 million Euro for 20 months therapy! b. Conflicts between a German lessor (house in Munich) and residents/tenants induce dangerous cardiac-vascular disturbances.

Ref. Authors et al.: IVR-2015-Washington (Int.Ass.Philos.Law) Progr.Book p.116/3,8,9, 124/5, 127/3, 129/3. World-Congr.Philos. FISP-2013-Athens Abstr.Book: 464-5,503-4,766. -2008-Seoul, Abstr.Book 338-9,363-5, DVD-2010, Vol. 4:101-8, 20:203-14, 45:229-237, 37:195-202. -2003-Istanbul 279-281. World-Congr. Bioethics IAB-2016 Edinburgh, 93-95. -Croatia-Istria-2008, 290/307. EACME-2015-Cagliari, 36-37, -2011-Istanbul, 64-65, -2010-Oslo, 55-56.

Conclusion. Institutes of medical ethics/philosophy and law could found interdisciplinary local-national-continental (European-etc.) –international scientific, esp. health-medical tribunals to an European/international academy for medical philosophy (EACME-2015 Cagliari/Italy) via network of selected centres/departments for medical philosophy/ethics, also medical law and psychology considering scientific and political problems, also giving practical recommendations, counteracting impossible situations (A.-D.), supporting UNO-Agenda21 for better education, health, ecology in all countries.

---

## **Clinical Ethics Consultation Service: an overview after one year of activity**

Session 4  
Room 4

Federico Nicoli<sup>1,2</sup>, Jean Pierre Ramponi<sup>2</sup> & Mario Picozzi<sup>1</sup>

<sup>1</sup>Center for Clinical Ethics, Biotechnology and Life Sciences Department, Insubria University, Varese, Italy; <sup>2</sup>Clinical Ethics Service, Domus Salutis Clinic, Teresa Camplani Foundation, Brescia, Italy

A Clinical Ethics Service has been opened at Domus Salutis Clinic in June 2016. The service has begun its activity following both the Core Competencies for Healthcare Ethics Consultation of the American Society for Bioethics and Humanities and the Document of Trento. The first document presents a definition of Healthcare Ethics Consultation with a particular attention to the resolution of uncertainties and conflicts regarding value-laden in health care. The second one is the first Italian Document (approved by the Italian Working Group of Clinical Ethics and Healthcare Ethics Consultation in October 2013) aimed at improving both the role of clinical ethics and the healthcare ethics consultation, as a central part of clinical practice, to better treat the sick and dying patients.

This new service is focused on three main activities: ethics consultation, education/training for health care professionals and research. Specifically the ethics consultant has the following functions: providing consultations about clinical cases

(the consultant is available to offer informed and prudent counseling about ethical uncertainties and to assist in mediating conflict for an ethical solution); improving clinical ethics education through the design, organization and development of a permanent and specific training for small groups or individual health care operators, administrative operators, agencies and commissions (it is developed thanks to the presence of the consultant in department meetings, in the case discussions, in training sessions for those who request it and in official moments of formation promoted by the Foundation); developing a research activity in collaboration with the clinical team, individual health professionals and administrative organs (it is carried out through the production of scientific papers and articles in collaboration with physicians and nurses of the Foundation and with national and international colleagues; the drafting of guidelines and protocols for the institution and linking with ethics departments and scholars operating at institutional, regional, national, supranational level).

Ethics consultation can be requested by the patient and the patient's family in order to establish clear definitions regarding their present dilemmas and their choices for the future. A consultation can also be requested by physicians, nurses and health care staff as support regarding both what a most appropriate choice may be and clarification of various available options.

After one year, the Clinical Ethics Service has been developing its activities in these fields (ethics consultation, education, research). This work aims to present a qualitative and quantitative analysis of the activities of the service to evaluate potentiality and criticality of the first work phases of this Service. In particular, the analysis starts from a questionnaire proposed to the operators that have used the service.

---

## **“We Will Stop Femicide”, A Platform Fighting against Gender-Based Violence**

Gulsum Onal<sup>1</sup> & Yesim Isil Ulman<sup>2</sup>

<sup>1</sup>Sisli Etfal Hospital, Istanbul; <sup>2</sup>Acibadem University School of Medicine, Istanbul

Session 3  
Room 1

Violence against women is now well recognized as a public health problem and human rights violation of worldwide significance. It is an important risk factor for women's ill health, with far reaching consequences for both their physical and mental health<sup>1</sup>. World Health Organization (WHO) defines violence against women as “acts or threats of acts intended to hurt or make women suffer physically, sexually or psychologically, and which affect women because they are women or affect women disproportionately”<sup>2</sup>. According to the Convention on Elimination of all Forms of Discrimination Against Women (CEDAW) (1979) “. . .any act of gender-based violence that results in, or is likely to result in physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life” should be ended on the basis for realizing equality between women and men through ensuring women's equal access to, and equal opportunities in, political and public life.

Yet, this issue has aggravated far more than enjoying rights in political and public life recently and transformed into a global problem threatening right to life of women who demand for their own fundamental rights and freedoms. By Istanbul Convention on preventing and combating violence against women and domestic violence (2011), Council of Europe condemned all forms of violence against women and domestic violence; recognized that violence against women is a manifestation of historically unequal power relations between women and men, which have led to domination over, and discrimination against women by men and to the prevention of the full advancement of women<sup>3</sup>.

As this is also a heated debate in Turkey, a civilian platform, “We Will Stop Femicide” (WSF) was established in 2009 so as to draw attention of the public on this issue and to produce solutions in order to overcome this human right violation<sup>4</sup>. The Platform works compatibly with the Istanbul Convention and it aims to stop all forms of violence against women and domestic violence; to protect women from violations of right to life as well as all fundamental rights and freedoms. WSF mainly activates to keep harmed women alive, to give victims shelter and humanitarian aid, to make them accede legal support. As a matter of fact, WSF has taken part as a stakeholder in enactment of the “Protection of Family and Prevention of Violence against Women Law” (No. 6284) and urges the Parliament and governmental bodies to monitor the requirements of law for the benefit and protection of wronged and mistreated women. According to the annually kept records of the Platform, the number of women who were murdered on these reasons is 328 in 2016<sup>5</sup>.

This paper will deal with the activities and functions of WSF, as an exemplary NGO to fight for women’s rights by focusing on its social determinants, by alerting authorities for prevention of gender-based crimes, by analyzing this human right issue within the scope of universal bioethical principles, human rights and dignity.

Sources:

<sup>1</sup>Krantz G, Garcia-Moreno C, Violence against women, A Glossary, *J Epidemiol Community Health* 2005;59:818–821.

<sup>2</sup>Violence against Women Definition and scope of the problem, July 1987 <http://www.who.int/gender/violence/v4.pdf> (Accessed on 14.02.2016).

<sup>3</sup>Council of Europe Convention on preventing and combating violence against women and domestic violence, 12 April 2011, <https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=090000168046031c> (Accessed on 14.02.2016).

<sup>4</sup>“Stop Violence Against Women” (Kadin Cinayetlerini Durduracagiz!) Official Internet Page, <http://www.kadincinayetlerinidurduracagiz.net/hakkimizda> (Accessed on 14.02.2016).

<sup>5</sup>“Stop Violence Against Women” 2015 Annual Report <http://kadincinayetlerinidurduracagiz.net/veriler/2551/kadin-cinayetlerini-durduracagizplatformu2015yili-raporu> (Accessed on 14.02.2016).

## **La cesárea a demanda: Un conflicto de valores y un dilema a resolver**

Session 4  
Room 7

Gabriel Orce

Facultad de Medicina – Universidad Nacional de Tucumán - Tucumán - Argentina

**Introducción.** La operación cesárea es una técnica usada en la práctica obstétrica como herramienta para la resolución de problemas que puedan producirse durante el intento o el desarrollo de un parto vaginal o cuando la vía vaginal es impracticable o inconveniente para una paciente determinada. El desarrollo de la medicina y los cambios en las conductas sociales han llevado a una ampliación de las indicaciones de esta cirugía a lo largo de los años. La tasa de nacimientos por cesárea ha aumentado enormemente en las últimas décadas sin un aparente aumento en la incidencia de patologías que las justifique. En la República Argentina, la tasa de operaciones cesáreas en el subsector de la seguridad social del sistema de salud es muy alta. Entre otras causas, el aumento se puede atribuir a la realización de cesáreas a demanda, definidas como la realización de una operación cesárea sin indicación médica precisa y a solicitud de la mujer embarazada.

**Discusión.** En esta ponencia analizamos el conflicto de valores reflejado por la cesárea a demanda a la luz de los clásicos principios de la Bioética. La intervención puede justificarse con el argumento del respeto a la autonomía materna. El conflicto se establece con los principios de no maleficencia y justicia: cualquier parto por cesárea implica más riesgos que un parto vaginal para la salud de la mujer y su hijo, afectando el principio de no maleficencia e imponiendo al feto, que no puede ejercer su autonomía, las decisiones de su madre y, al mismo tiempo, eleva los costos de la atención perinatal tanto para el sector público como privado y de las obras sociales en un contexto de escasez de recursos sanitarios. Otras circunstancias pueden justificar un pedido de cesárea, como por ejemplo una mujer que solicita la realización de una cesárea en la fecha en la que el padre puede estar presente por cuestiones laborales. En este caso se satisface el principio de beneficencia. Otro punto de discusión en este artículo es el dilema de quién debe realizar la tarea de controlar esta práctica. ¿Es tarea de los que dirigen la atención de salud de la población, de las instituciones sanitarias donde se realizan, de los dirigentes de las instituciones que las financian o del médico obstetra que se encuentra en contacto con la paciente?

Nuestra opinión es que, en orden a respetar los principios de no maleficencia y justicia, se debería desalentar la realización de una cesárea a demanda, cirugía posiblemente innecesaria. No obstante, la decisión de aceptar o no el pedido de una mujer embarazada debe estar fundamentada en una equilibrada ponderación de los valores en conflicto y de las circunstancias particulares de cada embarazo. La tarea de control de esta práctica es responsabilidad de todos los actores del sistema de salud.

---

## Place of bioethics in continuing education for nurses in Kharkiv National Medical University

Tetyana Ospanova, Iryna Sorokina & Mykhailo Myroshnychenko  
Kharkiv National Medical University, Kharkiv, Ukraine

For professional nurses, continuing education is essential to safe and effective nursing care. The amount of knowledge required to take care of patients cannot be obtained simply through experience on the hospital unit or at the bedside. In the professional tasks performance the nurse deals with a lots of ethical problems related to birth, death, interaction with the patient, transplantation, cloning and reproductive health, that is why the knowledge of ethics for the nurse is an important issue.

A Master of Science in Nursing and Bachelor's Science of Nursing programs were established at Kharkiv National Medical University. The teaching of Bioethics to Nursing students should satisfy the new ethical qualification requirements, so that nursing students include. The main goal of the teaching of Bioethics in the Nursing course is the formation of a specialist with a high level of ethical competence, morality, sense of respect and tolerance.

Professors of the department of Internal medicine propedeutics Num. 2 & Nursing, who teach Nursing students the discipline of medical deontology, internal medicine, palliative medicine discuss with the Nursing students the ethical problems, because this department is the place of the students' first contact with a sick person. Bioethics emerges as a required instrument for Nursing students to think over the daily reality and moral conflicts that permeate their practice. Most of these moral dilemmas are analyzed using the principle-based approach, which applies the four moral principles of justice, autonomy, beneficence, and non-maleficence. The professors remind that the nurse has to work with the different categories of the patients; the nurse creates for each patient an atmosphere of respect for his/her present and past, for his/her values, customs and beliefs; the nurse takes the necessary safety measures for the patient.

Pathological anatomy department plays a major role in the formation of professional ethics bases of Nursing students due to the using of dead bodies and macrospecimens as teaching aids. In classes the professors explain to the students that the moral norms that should be followed during autopsies, working with the macrospecimens originate from the main principle of medicine - humanism, ethical principles of respect for human dignity and autonomy of the person, Christian morality.

The basic principle of humanism 'the human - the highest value' is the premise of humane attitude formation to the person during pathomorphology studying. In the basis of humane attitude formation to the dead bodies, macrospecimens should be put the idea that the anatomical materials that promote the professional development of each student are the remains of people, each of which was unique and inimitable personality, so the students have to contact with the anatomical materials carefully and respectfully. Respectful attitude to the dead patients and their relatives implies the strict observance of medical confidentiality and unavailability of medical documentation for the random patients.

Thus, it is essential that Nursing students be capable of expressing values, knowledge and abilities when performing their function and that their actions be aimed to solve ethical problems appearing during the exercise of their profession.

---

## Quality of life in patients with chronic diseases

Session 4  
Room 2

Tetyana Ospanova, V. Lesovoy<sup>1</sup>, N. Zaozerskaya, A. Chernykova, Iryna Sorokina & Mykhailo Myroshnychenko

Kharkiv National Medical University, Kharkiv, Ukraine

**Background.** During the past decades, there was an increasing predominance of chronic disorders. People living with chronic diseases experience compromised quality of life (QOL), because entailing of physical, psychological and social issues.

The goal of the present paper is to study factors associated with QOL among patients with Chronic kidney disease (CKD) 5th stage, Asthma and Diabetes mellitus (DM).

**Method:** 112 patients with CKD 5th st., undergoing hemodialysis (HD), 102 patients with Asthma and 78 patients with DM participated in the study. QOL was rated by the Ukrainian version of Medical Outcomes Study Short Form 36-Item (SF-36). A total of 112 HD patients (M-57%, F-43%, mean age -  $40.83 \pm 1.21$  yrs, dialysis age -  $30.4 \pm 3.2$  months; mean Kt/V  $1.18 \pm 0.2$ ) were included. Asthma was uncontrolled in 45% patients, controlled in 55% patients. 38% of diabetic patients had compensated DM and 68% - subcompensated DM. Socio-demographics and clinical parameter characteristics (the diagnosis, treatment management, sex, age, body mass index, and blood pressure) were indicated.

**Results.** Total parameters: physical component summary (PCS), mental component summary (MCS), and separate scores of these scales were significantly decreased in patients of all groups.

Patients with the type 1 DM and the controlled moderate asthma demonstrate the highest level of PCS. On the score "Physical functioning" (PF) unexpectedly high rates were noted in HD patients, low - with type 2 DM, uncontrolled severe asthma. Surprisingly low values of this scale were found in patients with mild asthma, and high level of the PF was demonstrated by patients with type 1 DM.

High level of MCS was found in HD patients, with type 1 diabetes, moderate asthma; low - with type 2 diabetes, mild and severe asthma. Score "vitality" was reduced in type 2 diabetes and severe asthma; social functioning (SF) was high in HD patients, low - in patients with type 2 diabetes and severe asthma. The role of emotions was positively assessed by HD patients and negatively - in all other groups.

We regarded high level of MCS in HD patients as an indicator of the patient's adaptation to his new existence hemodialysis, the HD' adequacy, their hopes of continuing their lives, and the prospect of kidney transplantation in the future, and the good compliance of patients with hemodialysis staff.

Sufficiently high indices are also shown by patients with type 1 diabetes, especially in patients with younger age, absence of obesity, and hypertension. The lowest indicators of PCS and MCS were demonstrated by patients with type 2 diabetes and severe asthma. In case of type 2 diabetes, it is possible due to the more elder age

of patients, presence of overweight, hypertension, coronary artery disease, and etc. Severe asthma is characterized by fixed bronchial obstruction, frequent hormone dependence, resistance to therapy, which significantly reduces patients' QOL.

Conclusion. Research on patients with chronic diseases indicates that coexisting chronic diseases are associated with impaired QOL. Therefore, intensified early treatment of concomitant diseases and interventions for reducing psychological morbidity are associated with improved QOL.

---

Session 3  
Room 7

## **Fundamentación ética de las estrategias para la seguridad de los pacientes**

Rosa M<sup>a</sup> Pérez Capellades

Hospital Comarcal del Pallars, Lleida (Spain)

Introducción. Para justificar las políticas de seguridad clínica, las administraciones sanitarias se basan en dos modelos. El primero de estos modelos y el más conocido, es el modelo sistémico o de eventos adversos, que considera que los errores se producen en entornos complejos. El segundo modelo es el centrado en el profesional, que analiza las condiciones latentes que van a producir que un profesional cometa un error. El enfoque ético de la seguridad de los pacientes aporta otro abordaje, que es el de valores, derechos y deberes, para el cual algunos autores defienden tres fundamentos para una ética de la seguridad: un fundamento teleológico, un fundamento deontológico y un fundamento basado en la ética de la responsabilidad.

Hipótesis y objetivo. En un Hospital Comarcal, los criterios utilitaristas y económicos no son suficientes para justificar la seguridad de los pacientes, por el menor impacto económico o de demandas que generan los incidentes. A partir de esta idea, se hace necesario aportar otra visión de la seguridad clínica, que será la visión ética. No sólo las argumentaciones teleológicas sino también las argumentaciones éticas deberían ser tenidas en cuenta a la hora de defender las políticas de seguridad de los pacientes.

Metodología (materiales y métodos). Revisión bibliográfica respecto a los diferentes modelos que abordan los errores asistenciales y la seguridad de los pacientes, centrándonos principalmente en el modelo ético. Desde este enfoque, analizamos las aportaciones de las éticas teleológicas, deontológicas y de la responsabilidad.

Resultados. Para las éticas teleológicas y las teorías utilitaristas, el objetivo es maximizar los resultados positivos. A partir de éstas, se despliegan la mayoría de políticas de seguridad de pacientes, utilizando el argumento económico para las inversiones en torno a la seguridad. Para las éticas deontológicas el juicio moral se basa en valores y principios. La ética principialista es la más utilizada, con los 4 principios de beneficencia, no maleficencia, justicia y autonomía. A partir de esta ética, el principio de no maleficencia se considera la piedra angular de la seguridad clínica, juntamente con el de beneficencia. Actualmente se considera que no hay suficiente con las argumentaciones deontológicas ni con las teleológicas para explicar los juicios morales en seguridad; hay que utilizarlos complementariamente y hacer uso también de las argumentaciones deliberativas con las éticas de la responsabilidad con Hans Jonas como máximo representante.

Conclusiones. Se puede fundamentar la seguridad clínica reflexionando sobre la presencia de principios éticos, ya que en la prevención de los riesgos sanitarios se encuentran los principios bioéticos, los valores y las éticas de responsabilidad.

---

## **Informed Consent and the Royal College of Surgeons' Guide to Good Practice – Are Patients Giving Fully Informed Consent?**

Session 4  
Room 1

Ary Phaily<sup>1</sup>, Chudy Uzoho<sup>2</sup>, John Thomas<sup>3</sup> & Sanjiv Manjure<sup>1</sup>

<sup>1</sup>Luton and Dunstable Hospital, Luton, UK; <sup>2</sup>Nottingham University Hospitals NHS Trust, Nottingham, UK; <sup>3</sup>University Hospital of Wales, Cardiff, UK

**Aims.** Following the United Kingdom Supreme Court ruling of *Montgomery vs Lanarkshire*, the Royal College of Surgeons published guidance in the form of 'Consent: Supported Decision-Making' to help surgeons on the legal requirements on consent and patients' right. This study assesses the current state of consent in practice.

**Methods.** A retrospective study at a district general hospital of the consent process for elective orthopaedic operations over a 3 week period. Electronic records including consent forms and clinic letters were assessed against 14 criteria from the Royal College guidelines which were selected following discussion from the consultant body. Exclusions criteria included unavailable records, local anaesthetic procedures and cancellations.

**Results.** 89 patients (49 M:39 F, median age 54) had the following explained and documented during consent: Explanation of diagnosis (87.8%), Nature of treatment (82.0%), Benefits (57.3%), Risks (71%), Likelihood of success (28.1%), Follow-up process (33.7%), Alternative treatments (21.3%), Risks of alternatives (14.6%), Right to refuse (3.6%). Key points were recorded in 98.7% whilst 10% were given multimedia to take home. Only 6.7% of patients were given time to go and think about consent. Copy of clinic letters were sent to the patient and General Practitioner in 100% of cases.

**Conclusions.** Although documentation of diagnosis, nature of treatment and risks was satisfactory, morework needs to be done to improve consent document to meet new medico-legal requirements. Informing patients of the likelihood of success, offering alternative treatment options and their risks as well as the right to refuse treatment must be documented in order to avoid the potential for legal challenges further down the line. The introduction of proforma checklists, giving patients information leaflets and time to reflect will help protect surgeons and safeguard patients' right to informed consent.

---

## Stigma and mental illness in mass media

Josep Pifarré<sup>123</sup>, Jesús Cornejo<sup>1</sup> & Montserrat Esquerda<sup>134</sup>

<sup>1</sup>Universitat de Lleida; <sup>2</sup>GSS-HUSM; <sup>3</sup>SJD Terres de Lleida; <sup>4</sup>Institut Borja de Bioètica-URL

**Background.** Stigmatizing attitudes towards people with mental illness are frequent in most countries. Mass media are important in visualizing and in generating public opinion about stigma. Great effort has been done to minimize stigma in mass media, but results are probably not as good as expected. We hypothesize that stigma in newspapers has diminished but it continues nowadays.

**Methods.** Retrospective study. We compare stigma in news about persons with mental illness of a Spanish newspaper in three years: 1996, 2006 and 2016.

**Results and conclusion.** We found an improvement during these years, with less proportion of stigmatizing notices in recent years. However, we found yet negative stigmatizing notices in 2016, showing that there is a lot of work to do to minimize stigma towards people with mental illness. We discuss ethics implications, and we propose some strategies to improve this topic.

---

## Which core skills for Healthcare Ethics Consultations in Disaster Medicine?

Istvan Piffer Gamberoni, Federico Nicoli & Mario Picozzi

Center For Clinical Ethics, Biotechnologies And Life Sciences Department, Insubria University, Varese, Italy

Disasters, like epidemics and wide emergencies raise many ethical issues for the people involved, who include responders, public health specialists and policy-makers. A disaster is defined by the United Nations Office for Disaster Risk Reduction as a “serious disruption of the functioning of a community or a society involving widespread human, material, economic or environmental losses and impacts, which exceeds the ability of the affected community or society to cope using its own resources”. A Disaster is a result of interactions between hazards and manifold community elements, with differing vulnerability and capacity to cope with situations. The disaster dynamics depict the various fases like a circle: disaster preparedness, response, rehabilitation, reconstruction, development, disaster prevention, mitigation.

The requirements of the community for patient care and for research and surveillance vary case by case and are influenced by how risks are managed before, during and after events and by the type and magnitude of the consequences of emergencies when they occur. If core skills for disaster managers and health specialists are enough outlined, there is a paucity of literature regarding the core competences about Healthcare Ethics Consultations (HCEC) in disaster medicine.

If a health care ethics consultation (HCEC) is, “a set of services provided by an individual or a group to help patients, families, surrogates, health care providers, or other involved parties address uncertainty or conflict regarding values-laden concerns

that emerge in health care”, as defined by the National Center for Ethics in Health Care, it’s crucial to decline the Knowledge Areas like the nine ones proposed by the American Society for Bioethics and Humanities into the disasters ethical issues context.

The ability to analyze the boundaries between public health practice, including surveillance, and research and their ethical implications in emergencies, to define adequate processes for ethics review or to define ethically relevant criteria for triage, resource allocation and standard of care in emergency response and the expertise to discuss the professional duties of health care workers during public health surveillance, research and disaster management in emergencies, as reported by the WHO “Ethics in epidemics, emergencies and disasters: research, surveillance and patient care” training manual represent some of the core competences of a ethical consultant.

If the World Association of for disaster and emergency medicine (WADEN) has published a “Utstein-style template to uniform data reporting of acute medical response in disasters” to better perform research reports, it can be noted as missing in this master document, as in others, a lack of mentions about coping ethical issues.

It’s fundamental non only the presence of ethical guidelines about disasters management, from the planning phase to the mitigation one and, also the research one, but it’s important to argue about the relevance of the presence of a HCEC Service to Anticipate ethical challenges that may occur facing a disaster, how to assess the ethical frame on spot and to train operators and researches. For these reasons prominent to discuss about the core skills that a disaster medicine ethics consultant may own.

---

## **Truth-telling to a cancer patient about poor prognosis: a clinical case report in cross-cultural communication**

Mohammad Razai

University of Cambridge and London Northwest Healthcare NHS Trust

Session 1  
Room 3

Ethical principles are not mere abstract concepts of academic interest. They have to applied by care providers in the real world under complex, challenging and often perplexing conditions. This paper discusses, through the case of an ethnic minority patient with metastasis of bowel cancer, the ethical dilemma of truth-telling, withholding information and lying about poor prognosis. It highlights the complexities of applying ethical principles in a different cultural milieu, reflecting on different ethical frameworks and justifications. The paper also discusses some of the wider implications of the practices, issues and controversies of lying and truth-telling in cross-cultural communication relevant to clinical practice.

## Value of Life - Intrinsic or Personal?

Angelika Reichstein  
University of East Anglia, UK

The value of life is an important yet intricate aspect of bioethical debates. This paper will engage with two conflicting notions of value of life – intrinsic value and personal value – at the example of assisted dying debates in the UK.

According to the differentiation between intrinsic and personal value—as for example used by Ronald Dworkin— intrinsic value is the value every human life has, regardless of age, gender, race, or any other characteristic, it is a value par being human. Personal value on the other hand gets attributed to life by the person living it. The sanctity of life is an intrinsic value, applying to each and every life. The personal value of life, however, demands that every individual has a right to self-determination. While the intrinsic value of life cannot be lost and does not change, the personal value can diminish, for example through illness and suffering.

In debates regarding the legalisation of assisted dying, the two different notions of a value of life collide. Arguments in favour of assisted dying are based on the personal value of life, while those against focus on the intrinsic value. This paper will analyse the conflict and show how both should be engaged with in achieving a compassionate approach towards the regulation of assisted dying.

---

## A question of fairness: Shall cost be a criterion to withhold opioid-assisted therapy from elderly, incapacitated patients?

Stella Reiter-Theil<sup>1</sup>, Jan Schuermann<sup>1</sup>, Kenneth Duersteler<sup>2</sup> & Marc Vogel<sup>2</sup>

<sup>1</sup>Dept. Clinical Ethics, Psychiatric University Hospitals / University Hospital Basel, University of Basel; <sup>2</sup>Centre for Dependency Disorders, Psychiatric University Hospitals, Basel

In respect of demographic change, the number of older patients with substance abuse and addiction is on the rise (1). Within the liberal context of Swiss legislation severely opioid-dependent patients may receive opioid-assisted therapy (OAT). While being costly, OAT is effective in reducing heroin use associated risk behaviours, as well as mortality, and retaining patients in treatment. It is thus fully consistent with “harm reduction”, a leading paradigm in the care for patients with poor prognosis of regaining abstinence. However, OAT is still a matter of controversy.

Is it ethically justified or even requested to taper OAT in addicted elderly, incapacitated patients (EIP) in need of nursing care who are no longer able to obtain illicit drugs by themselves? Their lacking request for OAT might be a sequela of cognitive impairment. Here, OAT would neither prevent patient delinquency or self-infection, nor reduce harm resulting from prostitution for the procurement of drugs.

Or is it ethically – better – justified to continue OAT in this vulnerable group assuming that their special condition of “craving” is persisting, even if they can’t

communicate their subjective experiences? (Craving for drugs may be understood as a particular category of suffering.) It is, however, unknown and difficult to ascertain to which degree craving persists in cognitively impaired patients (2).

In the absence of an explicit dilemma where another patient group of comparable vulnerability would compete directly for the same resources, discontinuing OAT from the EIP group for financial reasons is weakly grounded. Rather, acknowledging OAT as a kind of “palliative care” for the EIP group appears justified by appeal to the principle of preventing harm allowing the patients to live through old age in relatively calm mode.

Void of medical evidence or ethical guidelines, decision making in this realm should acknowledge patient wishes, even in the incapacitated, by thoroughly exploring and observing the patient, also using advance directives or legitimised substitutes. Involved healthcare professionals and institutions should refrain from unconsented drug withdrawal and forceful deprivation with unknown effects on the patient’s subjective processes. However, experimental tapering may be tried on the basis of appropriate informed consent and close criteria-based monitoring allowing an adjustment of the protocol at any time (3).

The controversy will be illustrated by cases from Clinical Ethics Consultation in mental health care and somatic medicine also allowing to support inter-institutional agreements in order to prevent unfairness toward the vulnerable.

---

## **Broad consent for healthcare-embedded biobanking: understanding and reasons to donate in a large patient sample**

Gesine Richter<sup>1,2</sup>, Michael Krawczak<sup>3</sup>, Wolfgang Lieb<sup>1</sup>, Lena Wolff<sup>2</sup>, Stefan Schreiber<sup>4</sup> & Alena Buyx<sup>2</sup>

<sup>1</sup>Institute of Epidemiologie, Christian-Albrechts-Universität zu Kiel; <sup>2</sup>Institute of Experimental Medicine, Division of Biomedical Ethics, Christian-Albrechts-Universität zu Kiel; <sup>3</sup>Institute of Medical Informatics and Statistics, Christian-Albrechts-Universität zu Kiel; <sup>4</sup>Institute of Clinical Molecular Biology, Christian-Albrechts-Universität zu Kiel;

Biorepositories for medical research aim at the long-term storage of human biomaterial alongside associated data. Such collections are usually established for specific research projects. More recently, however, the large-scale collection and storage of samples left over from clinical routine has become popular in an approach termed ‘healthcare-embedded biobanking’. Although residual biomaterial from the clinic has been preserved for research purposes in the past, this systematic collection of biomaterial and data in large patient cohorts is a novel development.

Healthcare-embedded, hospital-based biobanking differs from non-hospital, often project-oriented biobanking in that donors are not recruited among healthy volunteers or patients outside the clinic, but get involved because they originally seek diagnosis or treatment. Moreover, the intended use of residual biomaterial is not normally confined to a specific research project or period of time. These differences have important impacts, not only in terms of the legal and ethical framework of biobanking, but also on the perception of patients and their willingness to consent.

Session 2  
Room 1

Since most scientific questions that can potentially be addressed by healthcare-embedded biobanking are unknown at the time the biomaterial is collected, the traditional paradigm of informed consent, known from clinical research, cannot be transferred easily to this type of collection. Recently, broad consent was thus recommended as an ethical option. Broad consent entails the provision of general information about the respective biobanking activity, but does not specify the individual research projects that will draw upon the biomaterial and data. This way, it provides researchers with sufficient flexibility to pursue a wide range of future, scientific agendas.

Regarding ethical acceptability, it is still unclear whether patients are willing to give broad consent in the first place, whether they truly understand, and why they ultimately either give or withhold broad consent.

In view of the increasing popularity of healthcare-embedded biobanking, a detailed empirical study about the ethical justification and acceptability of broad consent seems well warranted.

To ensure that healthcare-embedded biobanking with broad consent is both ethically acceptable and practically successful, the proportion of patients giving or withholding broad consent and their motivation need to be explored, including their relation to the level of comprehension of broad consent, in the immediate care context.

Since such research is still lacking, we set out to examine decision-relevant aspects of both comprehension and motivation in a large cohort of patients involved in a pilot implementation of broad consent-based healthcare-embedded biobanking in Northern Germany (n=760).

To the best of our knowledge, our study is the first to appraise these aspects in a large sample and ‘in the field’, i.e. at the time of consenting within a regular healthcare setting, thereby filling an important gap in the scientific literature. Overall, there is great willingness to give broad consent to the collection of leftover biomaterial and the use of routine data for research. Moreover, the better the understanding of patients, the higher is their willingness to get involved. Pro-social reasons appear to play a major role: Altruism, reciprocity, solidarity and gratitude were found to be more relevant for decision-making than objective or subjective knowledge, or objection to particular elements of the broad consent process, including non-reporting of findings. Therefore, future efforts to improve the information material used in healthcare-embedded biobanking should emphasise pro-social motivation, instead of focussing on the amount and precision of information conveyed.

---

## A matter of justice: moving from values to conduct

Session 4  
Room 2

Laia Riera Armengol & Gemma Torrell

Grup d'Ètica Societat Catalana de Medicina Familiar i Comunitària (CAMFIC)

**Introduction.** Our daily practice, as a general practitioners (GP), is imbued with values. In 2005, the Catalan Society of General Practitioners (Societat Catalana de metges de família [CAMFIC]) elaborated a consensus document with essential values to guide GPs: dedication, respect, proximity, loyalty, good judgement, equity and honesty. What does it entail to be a good GP? How do those values reflect our work? This work we are introducing aims to define representative behaviours for each value to better define our commitment to patients.

There is an implicit social contract between GPs and their communities that compels GPs to seek excellence in daily practice by guaranteeing equity and justice in assistance.

This document is unique in Spanish general practice and defines a desirable goal for becoming a better professional.

**Methodology.** In April 2014, through bibliographic research a frame to develop the document was established based on the British experiences of Good Medical Practise. Members of the Ethics Group of CAMFIC elaborated a list of conducts associated to each value. A first draft was shared with experts and consultants in medicine and ethics fields. A second draft incorporated their contributions and was shared with all CAMFIC members. The appropriateness and need of such a document was further debated in two face-to-face meetings and outcomes from these meetings were included in a new version. The CAMFIC board approved the document containing 133 behaviours.

A participative process with all CAMFIC members was conducted online. Members had 10-15 days to provide their level of agreement with the behaviours that were associated to each value, including the option to text freely.

Overall, 535 answers were received and showed a high level of agreement, in no case less than 70%. In addition, 594 comments were received and qualitatively evaluated. This results were used to reformulate some behaviours, shaping the final document that inspires this abstract.

**Conclusions.** There is a high level of interest in discussing the values that drive a GPs behaviour in clinical practice. The high level of agreement on the behaviours proposed for each value suggest that they are representative of the GP values. The consensus document is relevant because it promotes reflexion and continuous learning, leading professionals to a goal of excellence guaranteeing a fairer medical care.

## **An ethical dilemma in communicating genetic information in families: respect for autonomy and privacy in conflict with beneficence and nonmaleficence.**

Adelheid Rigo<sup>1</sup> & Johan Stuy<sup>2</sup>

<sup>1</sup>University College Odisee; <sup>2</sup>Free University Brussels

In the future genetic information will be more numerous and easily accessible. Genetic information has a dual character: it's as well personal, individual as familial information. The latter assumes a moral duty of the individual proband, from whose blood the information was collected, to inform her/his relatives about the genetic risk circulating in the family. So, the autonomy of the relatives is likewise respected: they can decide for themselves if they want or don't want to know their individual genetic risk.

This paper focus on the rare case where the proband doesn't want to inform her/his relatives about the genetic risk in the family and forbids his doctor-genetic counselor to do so. Can a doctor/genetic counselor renounce her/his duty to keeping medical information confidential and inform the relatives about their potential risks? The doctor/genetic counselor is caught in an ethical dilemma between on the one hand respecting the autonomy of his proband and her/his informational privacy and on the other hand acting beneficent towards the relatives or prevent them from harm.

In Belgium there are 8 centers for human genetics who consider 'appropriate psychological and social support' as core competences (Skirton, 2010). Their social support accentuates the involvement of family members. They will always try to convince the proband to communicate the genetic information to relatives.

A doctor/genetic counselor is by the Belgian 'Law on Patients' Rights' (2002) restrained to the duty of confidentiality. In the rare case where the proband is adamant in her/his refusal, a doctor/genetic counselor can appeal to 'a conflict of interests'.

This 'force majeure' is a juridical concept from criminal law that allows doctors to break their duty of confidentiality in exceptional circumstances.

Is this policy in Belgium, considering the increasing amount of genetic information, still adequate?

To analyse this specific ethical dilemma, we investigate the standpoints in the international scientific literature. We systematically searched electronic databases and bioethical books from 1999 until 2016.

We divide the standpoints in three different positions:

1. Although the family holds an important place in the counseling process, respect for the autonomy and privacy of the individual proband/patient prevails. In the final decision, the interests of relatives are recognized so far as one can prove that a particular relative is at risk for serious harm.
2. The interests of the relatives are extensively taken into account and are recognized. Formal procedures are invoked by a refusal of the proband to communicate risk information with relatives. Nevertheless the final decision is up to the proband.

3. Genetic information is by nature familial so there should be no restraints for blood relatives to know. The family is the ‘unit of care’. Acting beneficent and preventing relatives from harm by overriding the probands’ right to confidentiality, starts from the assumption that relatives want ‘to know’.

We prefer the first standpoint for Belgium, even when more genetic information in different branches of medicine will be available. The centers for Human Genetics dispose of psychosocial expertise and are family-oriented in their counseling. We advocate that when genetic information is used in other disciplines of medicine that, apart from the genetic know-how, also the psychosocial skills to ease communication in families will be taken in as well.

---

## **End-of-life decisions and people with disabilities: disability rights or care ethics subject?**

Session 3  
Room 4

Daniela Ritzenthaler

University of Zurich, Switzerland

Dans le débat bioéthique, il y a très peu de recherche et de réflexion philosophique concernant les personnes en situation de handicap intellectuel. Cette présentation décrit les résultats d’une thèse en pédagogie curative et en éthique qui a été présentée à l’Institut des sciences de l’éducation à l’Université de Zurich. Le projet de recherche qualitative a analysé des décisions thérapeutiques en fin de vie chez les personnes présentant une déficience intellectuelle habitant dans une institution sociale.

La présentation va au-delà de la description des résultats empiriques sur les décisions en fin de vie et met l’accent sur les dimensions éthiques et philosophiques.

En premier lieu, elle souligne que l’importance de l’auto-détermination et des droits des personnes en situation de handicap est une valeur importante dans la déontologie du personnel éducatif. Cela est également vrai pour le personnel des différentes professions du système de santé impliquées dans les soins palliatifs ou dans les choix au plan thérapeutique. Les droits des personnes en situations de handicap se voient renforcés par diverses juridictions dans plusieurs pays européens, mais également dans la déclaration de l’ONU sur les droits des personnes en situation de handicap. La présentation souligne l’importance de cette perspective et du renforcement de ces droits. En même temps, elle démontre les limites qui lui sont posées dans le cadre clinique par l’incapacité de discernement des patients concernées. En plus, la volonté présumée des patients est rarement connue.

Finalement, une approche de Care-ethics est présentée, dont l’argumentation se base sur la nécessité de prendre ces décisions existentielles en menant un débat éthique structuré avec les tous intervenants de la décision, en suivant une attitude de vouloir comprendre la personne dans son cadre de vie et de remettre en question ses propres valeurs et intuitions. Cela signifie que la décision se fait avec le patient, ou son représentant légal, et avec médecin traitant. En Suisse, les représentants légaux sont souvent des proches de la famille ou parfois des assistants sociaux assignés à cette tâche par un mandat professionnel. Pour les personnes vivant en institution sociale, l’expérience montre qu’il est crucial pour la suite des soins palliatifs et pour

les relations entre le personnel d'accompagnement et la famille, qu'une personne qui représente l'institution participe à la prise de décision. Cela non pas pour influencer la décision, mais pour connaître les raisons des décisions prises (d'un point de vue éthique et médical). Ce savoir est très important et doit être transmis à toute l'équipe qui s'occupe de la personne en situation de handicap. Toutes les personnes interrogées ont souligné l'importance de la communication du savoir médical pour que la personne puisse être soignée au mieux. Pour que les conflits suite à des décisions thérapeutiques prises, qui arrivaient relativement souvent, diminuent, une bonne communication est indispensable. Cela implique également la capacité de remettre en question ses propres valeurs pour agir dans l'intérêt de la personne concernée.

---

Session 4 **Gender and dementia bias. Can biology explain everything?**  
Room 6

B. Robles<sup>1</sup>, P. Valls<sup>2</sup>, M. Tramunt<sup>3</sup>, D. Muñoz<sup>3</sup>, J. Graells<sup>1</sup> & N. Parellada<sup>3</sup>

<sup>1</sup>Parc Sanitari Sant Joan de Déu; <sup>2</sup>University of Barcelona; <sup>3</sup>ABS Montclar. Servei d'Atenció Primària Baix Llobregat Centre

**Justification.** There are numerous recent studies on the existence of a gender bias in many diseases and even research (including experiments conducted on animals). From an ethical reflection about equity, it is very important to know to what extent the differences detected are due to biodiversity because it is possible that they are motivated, at least in part, by social attitudes and professionals towards affected women.

**Objective.** Describe the clinical and healthcare characteristics of people diagnosed with dementia in Primary Care depending on the sex of the patient and caregiver.

**Methods and materials.** Observational cross-sectional study of 227 cases with a diagnosis of dementia in all its variants according to ICD-10 coding, collecting socio-demographic variables, and clinical care.

**Results.** Were found greater age (83 versus 78,  $p < 0.001$ ) and lower education in women (16.7% illiteracy versus 6.8%). Alzheimer disease was most common subtype, although the prevalence was higher in women (55.4% vs 39%). The institutionalization (51.1% versus 32.2%;  $p = 0.01$ ), polypharmacy (7.6 active ingredient / person versus 6.1;  $p = 0.02$ ) and the use of psychotropic drugs are higher in women while attendance at hospital emergency and Primary Care is lower ( $p = 0.033$ ).

The usual caregiver is a woman (64.8%;  $P < 0.001$ ). Patients cared by their daughters attend less to UH ( $p = 0.017$ ) and are more likely to receive a specific treatment for dementia.

**Conclusions.** The profile of dementia in PC differs between men and women. The standard patient would be a woman, older than in the group of men, less educated, with advanced dementia, more "medicalized", more institutionalized and less frequenter at hospitals and Primary Care. The data suggest that women with dementia may generate less overhead direct healthcare but more impact and socio-medical drug.

The greater institutionalization and consumption of drugs (specific for dementia and psychoactive) suggests more impact for the family when a woman is ill. In our series, a woman affected by dementia is less likely to remain at home throughout the course of the disease and is more exposed to adverse drug effects.

Data show significant differences between men and women suffering from the same diagnosis that is difficult to explain using only clinical or biological variables. Beyond ethical considerations evoke from the principle of justice (fairness), the study also invites us to think about the "role" that continues developing greater woman, beyond the end of the theoretical "active working life", in the current complex households, at least in the context of socio-demographic in our series (urban suburbs of a big city).

This was a retrospective observational study that does not allow establishing cause-effect relationships. It offers suggestive data but should be supplemented with prospective designs that allow better control confounding variables in order to clarify the relative impact of social factors versus biological the differences.

---

## **Burden of treatment in face of childhood cancer: A quantitative study based on medical records of deceased children**

Michael Rost, Tenzin Wangmo, Milenko Rakic, Elaine Acheson & Bernice Elger  
University of Basel

Session 3  
Room 3

**Introduction:** Worldwide, approximately 200.000 children are diagnosed with cancer each year. Apart from disease associated symptoms, children and their families continuously experience burden due to treatment. Lived experiences of children with cancer and their families have been described as an interrupted one with limited opportunities to engage in leisure activities, difficulties in sustaining existing friendships, and loss of a normal family life. The cancer diagnosis thus has an interruptive effect on the everyday life of the affected person and his or her family. The goal of the study is to assess the actual burden of treatment for the children and their families, and evaluate whether the burden differs by different type of cancer.

**Methods:** We retrospectively analyzed medical records of deceased children. Inclusion criteria were: a) cancer diagnosis and treatment in one of the participating centers in Switzerland, b) less than or equal to 18 years of age at diagnosis, and c) death due to cancer or treatment-related complications between 2008 and 2014. A final set of 211 children met the inclusion criteria. A data extraction form was used to gather data on the following aspects from the medical records: demographics, diagnosis and treatments information, decision-making, and information surrounding death of the child. First, variables were analyzed descriptively. Second, three diagnosis-based subgroups within our sample, namely leukemia patients, CNS neoplasms patients, and patients with other diagnoses were compared.

**Results:** In general, the children and their families faced a high number of distressing inpatient stays and long hospitalizations along with waiting times and a highly interrupted daily life. Results of comparisons between three diagnostic groups

suggest that pediatric leukemia patients faced the highest burden of treatment compared to patients with CNS neoplasms and patients with other diagnoses, indicated by inpatient stays and days being inpatient (more than CNS neoplasms patients), inpatient-proportion and days being inpatient during the last month of life (more than both CNS neoplasms patients and patients with other diagnoses). Furthermore, leukemia patients more frequently died in the hospital than the overall sample. Finally, across diagnoses parents were present at the time of death in almost all cases.

Discussion: Our main finding of a higher burden of leukemia treatment underscores the need for a raised awareness among the treating staff of leukemia patients' significant burden. This is particularly relevant, since burden of leukemia treatment for children might be underestimated given the comparably good prognosis for this diagnostic group and since leukemia represents the most common type of childhood cancer. Therefore, health care professionals need to be aware of the characteristics of leukemia treatment, for example highly disruptive effects on daily lives due to higher number of clinic visits, and to constantly apply this awareness to the entire family.

---

## **Cutting to the core domains of pediatric palliative care: A critical analysis on international guidelines**

Session 3  
Room 3

Michael Rost, Eva de Clercq, Tenzin Wangmo & Bernice Elger  
University of Basel

Introduction: Improved survival rates of pediatric patients with life-threatening and life-limiting diseases have led to a higher number of children needing pediatric palliative care (PPC). Several barriers to adequate implementation and sufficient provision of PPC have been identified. Various scholars have focused on the problem of conceptual confusion between palliative and hospice care and on the lack of a shared understanding of palliative care in pediatrics. This study aims to contribute to this debate by looking through the lense of international guidelines on PPC and by exploring what the core domains of PPC are.

Methods: A literature review was conducted using PRISMA systematic review of literature and searching five online databases: Scopus, PubMed, PsycInfo, Web of Science, and CINAHL. Additionally, we did a google search and scanned the member societies of the International Pediatric Association for further guidelines. A final set of 11 international guidelines on PPC published between 1998 and 2013 were included.

Results: All documents identify four core domains of PPC, namely physical, psychological, social and spiritual care. Psychological care, social care, and spiritual care lack conceptual clarity as their use is inconsistent and sometimes contradictory both within and across guidelines. Psychological care is not sufficiently demarcated from emotional care and social care is often conflated with psychosocial care. The domain of spiritual care is frequently mentioned in connection with existential or religious care, but the difference between these concepts remains unclear.

Discussion: It is important to examine how this conceptual confusion affects the quality of PPC. First, the term emotional care might reinforce the assumption

that children lack decisional capacity and therefore decrease the likelihood of their involvement in end-of-life decision-making. The notion of psychological care, by contrast, covers a wider spectrum of a child's needs as it, for example, also involves the child's cognitive needs. Second, unlike social care, the term psychosocial care more directly refers both to social relations and their impact on the person's psychological state. This is vital, since it is not a social relation per se but its importance for the child's well-being that needs to be considered by the treating staff. Third, religious care and existential care are mostly subordinated to spiritual care and the latter therefore is more inclusive and preferable. Besides, it offers a more neutral stance than religious care, especially within today's pluralistic societies. Furthermore, the way in which each PPC domain is understood determines which occupational group is involved in PPC and consequently, how the different domains of care are implemented and collaborate. Diverging understandings among the PPC team members can hinder the coordination of an effective team and might cause interpersonal conflicts and competition within the team. In conclusion, a shared understanding and unambiguous use of terms have to be envisaged in order to facilitate quality PPC.

---

## **Sustainability of national health services and justice: the case of new DAAs for HCV in Italy**

D. Sacchini, P. Refolo, R. Minacori, L. Craxì & A. G. Spagnolo

Institute of Bioethics and Medical Humanities, "A. Gemelli" School of Medicine,  
Università Cattolica del Sacro Cuore, Roma

Session 2  
Room 3

**Background** - Direct acting antivirals (DAAs) for hepatitis C virus (HCV) have quite changed the therapeutic routine in the last few years. Reported rates of sustained virological response (SVR), exceed 90% in all patients subgroups. Other, even more effective, DAAs combinations are being developed for use in the most difficult to treat and advanced patients, aiming for 100% of SVR in 100% of cases. The perspective is the eradication of HCV and reduction of main complications: liver cirrhosis and hepatocellular carcinoma.

**Aim and Methodology** - Dealing with justice issues related to DAAs for HCV in Italy through the analysis of available literature and documentation.

**Results** - The ethical principle of beneficence/non maleficence is fulfilled for new DAAs. Otherwise, the principle of justice in a welfare context, like Italian National Health Service (NHS), generally requires "to give everyone his/her own" to feed citizens' health needs. Anyway, in a setting of restricted access due to DAAs costs, availability and the wait for even better and universally applicable regimens is the crucial knot to deal with from justice perspective, also considering the need for a balance both of NHS expenditure and "inter nosological" fairness (e.g., oncology, neurology, etc.). So, the selection of patients for immediate treatment or deferral entails adherence to established and ethically accountable policies. In Italy, as well as in other countries, the early solution in 2015 was a stratification of patients for prioritization of treatment according a "needs-based" approach, which means allowing IFN-free DAAs treatment in patients with advanced fibrosis or cirrhosis,

while keeping on hold persons with lesser stages of liver disease, through ‘informed deferral’ policies aimed at saving a really informed consent.

Another justice issue is the conflict between the patient’s “right to care” and NHS economic charge due to the prevalence of HCV+ patients  $\geq 70$ yy (nearly half of overall infected subjects). The question is: given limited resources, why paying DAAs therapy for HCV+  $>70$ yy (with compensated liver disease, including cirrhosis) since life expectancy is similar to that of HCV- (except for decompensated cirrhosis)? Save for clinical benefit, this selection can be justifiable on condition that a punctual social/individual information be provided, also strengthening patient/public involvement. Moreover, a fair access to DAAs necessarily works through a continuous clinical/epidemiological follow-up aimed at preserving the primacy of patient’s clinical benefit in an overall sustainability, also paying attention to different impact of DAAs in different subgroups. Since the update of DAAs evidence, Italian Medicines Agency (AIFA) has identified in March 2017 the new priority reimbursement criteria for the treatment with the new DAAs. The goal is to treat all eligible patients preserving welfare justice and sustainability.

Conclusion - Even if the price of new DAAs will be reduced through competition and patent expiration, the phenomenon of high drug costs will go on in the next decades and we need proper tools to face the problems of distributive justice that come with it, starting from a clear declaration of which justice approach is assumed, and consequently, collaboration among all stakeholders.

---

**Clinical ethics consultation as “shared document”.**  
**Emerging ethical and medico-legal issues: the experience of**  
**IBioMedH-UCSC CEC Service (2005-2016)**

Session 4  
Room 3

D. Sacchini, B. Corsano, P. Refolo, R. Minacori & A. G. Spagnolo

Institute of Bioethics and Medical Humanities (IBioMedH) “A. Gemelli” School of  
Medicine, Università Cattolica del Sacro Cuore (UCSC), Rome (Italy)

Background - The clinical ethics consultation (CEC) aims to help patients, relatives, caregivers and healthcare professionals to cope with ethical issues arising in patient care. CEC can be drafted in two different ways: 1. CEC provided by clinical ethics consultant requested by clinical wards; 2. CEC as “shared decision-making document” (SDM-D) among different “bedside” stakeholders (patient, relatives, healthcare professionals, health managers) aimed at an agreed advanced clinical planning, namely in dilemmatic/uncertain settings. In fact, SDM is “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al., 2010)

Aim - Assessing rising ethical/medico-legal issues in clinical cases requested for CEC and addressed through SDM-D.

Methods - We examined retrospectively SDM-Ds provided by IBioMedH-UCSC CEC Service and requested from different clinical Departments of “A. Gemelli” University Hospital Foundation (starting from January 2005 to December 2016),

examining clinical indication, patient's preferences, quality of life; context, in the light of personalist bioethical approach (Sgreccia, 1986).

Results - 53 SDM-Ds out of 173 CECs were setup from 2005 to 2016. Clinical Departments that requested clinical ethics consultation were: Reproductive and maternal-Foetal Diseases (15, 28

The following main ethical issues were recognized: cardiopulmonary resuscitation; tracheostomy, ectopic pregnancies; inducing childbirth; mechanical ventilation; palliative sedation.

Possible ethical/medico-legal issues were identified: problems of communication and understanding between the parties; patients/family difficulties to identify benefits/burdens of treatments proposed by physicians and the patient's best interest; incomplete patient's understanding of physician's clinical goals; the patient/family request to join the discussion and to share the decisions concerning treatments; the fear of family that the doctors are not doing enough for the patient; for end-of-life patients, the fear that doctors will do unnecessary treatments that produce suffering; the patients/family perception to have distant and seemingly irreconcilable positions with those of the doctors. The different reasons for dissatisfaction of patients/family seems related not to physicians' technical skills, but to relationship issues. We observed that relationship difficulties could complicate other issues. In all cases examined, SDM helped to overcome potential conflicts, incomplete understandings or misunderstandings. The consequence of SDM was that no complaints has subsequently developed from these cases, some of which were particularly sensitive.

Conclusion - In our experience, the CEC provided through SDM-D can help: the optimization of the choice of proportionate treatments; to strengthen patients/family-doctors relationship and, at the same time, reduce the risk of complaints/disagreement; to analyse from the ethical point of view, for all the parties, the most problematic aspects of clinical situations and the possible solutions for a really SDM. The CEC-SDM-D can also clarify the goals of care for patient's best interest.

---

## **The dual use of research ethics committees. Why professional self-governance falls short in maintaining the balance between academic freedom and biosecurity**

Sabine Salloch

Institute for Ethics and History of Medicine, University Medicine Greifswald, Germany

Dual Use Research of Concern (DURC) constitutes a major challenge for research practice and oversight on the local, national and international level. Cases of ethically questionable research in biology and biosciences have attracted considerable attention in the last years such as the artificial synthesis of a live polio virus from scratch or the reconstruction of the Spanish flu virus. There are extensive international debates on how to regulate DURC with respect to research practice, funding and publishing. The situation in Germany is currently shaped by two competing suggestions on how to regulate security related research: The German Ethics Council as an independent political advisory body suggested a series of preventive measures,

Session 1  
Room 4

including a national legislation on DURC. Competing to that, the German National Academy of Sciences and the German Research Foundation as two major professional bodies presented a strategy which draws on the self-regulation of science and, inter alia, suggests extending the scope of research ethics committees (RECs) to an evaluation of DURC. In the presentation, this current situation is taken as an occasion to further discuss scope and limits of professional self-regulation with respect to security related research. In particular the role of RECs as professional bodies is analyzed in referring to the theoretical backgrounds of professionalism. Two sociological key features of professionalism – ethical orientation and professional self-regulation – are discussed with respect to professional behavior in biomedical science. Subsequently, both attributes are analyzed in dealing with the question whether RECs are suitable to evaluate DURC-suspected research. As a conclusion, it is stated that issues of biosecurity transcend the boundaries self-regulation within the scientific community and that a more comprehensive strategy should be implemented encompassing both, professional self-governance and legal oversight.

---

## **Ethical Expertise in Ethics Consultation: An empirical-ethical analysis of concepts and implications for evaluation research**

Session 4  
Room 4

Jan Schildmann<sup>1</sup>, Joschka Haltaufderheide<sup>2</sup>, Stephan Nadolny<sup>3</sup> & Jochen Vollmann<sup>1</sup>

<sup>1</sup>Klinikum der Universität München, Campus Großhadern; <sup>2</sup>Abteilung für Medizinische Ethik und Geschichte der Medizin Ruhr-Universität Bochum; <sup>3</sup>Fachhochschule der Diakonie Bielefeld

**Background.** Evaluating ethics consultation (or other models of clinical ethics support) has been at the centre of a considerable number of research projects. Up to present there are many suggestions but little consensus about how to evaluate what. One possible reason for the current status are the numerous goals and methods of ethics consultation. In this presentation we will make the case that different concepts of ethical expertise which underlay the different models of ethics consultation contribute to the present debate about appropriate evaluation of ethics consultation. Furthermore we argue that clarification of the underlying concept of ethical expertise can contribute to a more consistent approach to evaluation of ethics consultation.

**Methods.** We will use conceptual frameworks as method of complex intervention research to make explicit differing notions of ethical expertise underlying different models of ethics consultation. Subsequently we will demonstrate in how far clarifying the understanding of ethical expertise within the context of different models of ethics consultation can contribute to a better the definition of outcomes in evaluation research.

**Results.** The concepts of ethical expertise as discussed in the literature show differences regarding fundamental epistemological, normative as well as empirical premises. Parts of these differences are reflected in the different models of ethics consultation. Using conceptual frameworks as an element of complex intervention research we illustrate some of these differences taking the examples of “proactive”

and “deliberative” models of ethics consultation: the ethical expert in the former model is assumed to be able to detect, analyse and solve ethical issues in clinical practice the focus of the ethical expert. In contrast ethical expertise according to the “deliberative model” is developed through a process of exchanging views and values relevant to a moral problem in practice between health professionals and other stakeholders who search for consensus. As we will demonstrate in our presentation the aforementioned and further assumptions with regards to ethical expertise are crucial with regards to defining appropriate outcome criteria in evaluation research.

Conclusion. Different concepts of ethical expertise are contributing to different goals and mode of ethics consultation. To be able to define outcome criteria which match specific models of ethics consultation it is important to make explicit the often implicit notion of ethical expertise.

---

## **End-of-Life-Care: Making Ethics Consultation Visible**

Kurt W. Schmidt

Center for Medical Ethics. Agaplesion Markus Hospital. Frankfurt (Germany)

Session 3  
Room 2

Although Clinical Ethics Consultation (CEC) has been established for many years and is known to longstanding staff, patients and next-of-kin usually have their first contact with CEC as the result of an (unplanned) stay in hospital. Even if somebody has informed them about it beforehand, it is still difficult for next-of-kin to imagine what will happen during a consultation because of the stress they are under and the decisions they have to make. Having often experienced this problem, our Ethics Committee decided to make a video showing the course of such a consultation. This video is available to next-of-kin or other interested parties on the internet and can also give hospital staff a better insight into the procedure.

For the Ethics Committee, it was not only the finished video which was important, but also the creative process and writing of the screenplay: the video shows an anonymized consultation in which all the participants “play” themselves; only the two family members are played by members of staff. But which elements of an ethics consultation regarding end-of-life-care was the video to highlight? Which elements were particularly important? Justice? Vulnerability? In writing a screenplay for the internet, all participants were forced to reach an agreement about its central content and principal message in the full knowledge that their underlying approach or method would become “public”. One of the things which came out of this process was the importance of the right “atmosphere” in a consultation, and that this – and not only the contents – should also be captured in the video. Technical support (filming, soundtrack, editing) was provided by professionals.

Following an introduction, the talk will include a presentation of the video (7 minutes) and a report of the experiences resulting from it.

## Opportunities and risks of supported decision-making in dementia research: An ethical analysis

Matthé Scholten<sup>1</sup>, Jakov Gather<sup>12</sup> & Jochen Vollmann<sup>1</sup>

<sup>1</sup>Institute for Medical Ethics and History of Medicine, Ruhr University Bochum;

<sup>2</sup>Department of Psychiatry, Psychotherapy and Preventive Medicine, LWL University Hospital, Ruhr University Bochum

According to the interpretation of the Committee on the Rights of People with Disabilities (the Committee), article 12 of the United Nations Convention on the Rights of People with Disabilities (CRPD) represents a radical departure from the widely accepted functional approach to competence assessment, along with acknowledged procedures of substitute decision-making, in favor of a new paradigm of supported decision-making. Although we share the Committee's concerns about the discrimination of persons with mental disabilities and welcome the development of new capacity-enhancing tools, in this presentation we express several reservations regarding the model of supported decision-making proposed by the Committee.

Our main worry is that on the proposed model supported decision-making runs the risk of turning into masked substitute decision-making. This in turn renders persons with dementia vulnerable to abuse and exploitation. In particular, we show that supported decision-making without capacity assessment (1) increases the risk of undue influence, (2) exempts support persons from responsibility for the decision to take part in research along with its possible consequences and hence fails to provide proper checks and balances and (3) fails to specify criteria for the allocation of decision-support. To forestall these adverse consequences, we propose an alternative model of supported decision-making that involves a more limited and case-specific application of decision-support combined with a clear idea of the individual competence of persons participating in clinical dementia research.

---

## **“I think that a country, a society is worth only as much as it treats their weakest.” – Subjective views on health, illness and the provision of care of three involved parties in home nursing.**

Anna-Henrikje Seidlein<sup>1</sup>, Ines Buchholz<sup>2</sup>, Maresa Buchholz<sup>2</sup> & Sabine Salloch<sup>1</sup>

<sup>1</sup>Institute for Ethics and History of Medicine, University Medicine Greifswald; <sup>2</sup>Institute for Community Medicine, University Medicine Greifswald)

Introduction. Conceptions of health and illness have been widely discussed in the philosophy of medicine. Parallel to these theoretical debates, numerous empirical research projects have focused on subjective perspectives in relation to specific diseases and have shown their significance, for example with respect to therapeutic adherence and rehabilitation. However, only few studies have so far investigated the personal views and meanings of complex multimorbidity requiring long-term home nursing.

Methods. Data was collected by conducting semi-structured qualitative interviews with eight lay caregivers, ten professional caregivers and ten care-recipients

in long-term home nursing arrangements in the Northeastern part of Germany as an economically weak region with low population density and a high proportion of elderly citizens. The participants were asked about their lived experience and understanding of health and illness. Furthermore, the interviews intended to capture the participants' perceptions of the appropriateness of care. All interviews were audio-taped and literally transcribed. Qualitative content analysis according to Mayring was performed using MAXQDA 12 software.

**Results.** Illness is described as something mainly related to body symptoms (e.g. pain), whereas health is understood as a mental and emotional well-being, for which social relationships (e.g. family ties) play an outstanding role. Health is considered as having a less concrete character. It is seen as a capability that enables the participants to live their own lives whereas illness is linked to the loss of self-fulfillment. The evaluation of the provided nursing care varies in the views of the different stakeholders and with respect to various aspects of daily life: Nursing professionals observe overtreatment, inter alia, with respect to personal assistance on body care. Reasons are seen in financial disincentives and the wish to provide assistance which, however, leads to a loss of self-care skills and independence. Underprovision of care, as experienced by care recipients, is particularly described as a mismatch between the desired social inclusion, communication and mobility and the self-perceived current situation. Additional services are available, but are perceived as luxury and therefore only add-ons. Professional caregivers are aware of those needs and sometimes make extra efforts to meet their clients' wishes. Lay caregivers perceive most of the problems concerning underprovision of care as being related to a missing delivery of personal aid and care equipment, especially the bureaucratic obstacles to overcome in order to receive the desired goods.

**Discussion.** The desire for social participation was a major theme of all participants. It is a prerequisite for subjective well-being despite suffering from multiple chronic conditions. A narrowed understanding of professional care, therefore, ignores social inequality and their impact on care arrangements. Deficits in the supply for care-recipients especially occur in aspects which can be bought as extra services.

**Conclusions.** The remuneration system for long-time home nursing should be further discussed. Long-term care insurance does not meet all aspects of care perceived as relevant for subjective quality of life by care-recipients. Hence, there is an additional need for innovative concepts meeting the challenge of comprehensive care, particularly in economically weak regions with low population density.

---

Session 1  
Room 1

## Getting Clearer about Big Data and its Ethical Issues

Mark Sheehan

The Ethox Centre, Oxford University

In this paper I propose an account of what makes Big Data and research using Big Data techniques new and different. I do this with a view to trying to understand if there are any distinctive ethical issues that arise in this context that are not captured in the more usual discussions about data-based medical research. In the second part of the paper I use this account to examine the ethical issues that medical research using Big Data raises and how we might go about addressing them. In the concluding section I begin to sketch an account of the ethics governance of this kind of research that is well equipped to deal with the issues that Big Data research raises.

---

Session 4  
Room 5

## Evidence or bumbledom: nootropics between scientific values and public request

Sergey Shevchenko

Institute of Philosophy, Russian Academy of Sciences. Department of Bioethics, Pirogov Russian National Research Medical University

An American philosopher Larry Laudan considered values (along with facts and methods) a significant part of science. Contemporary science openly declares the trend towards democratization and medicine isn't exception. Therefore, values of society influence and structure interior values of science.

Evidence is a paradigmatic ground of contemporary biomedicine. Healthcare regulators and expert boards consider statistical proof of safety and efficacy as a condition of routine use of a substance or treatment method. And this condition is related to public health and that's why is considered to be a component of public values.

But can we really identify a social request of evidence, or evidence is only an interior scientific value? And if the second statement is true, how professional community should take public needs into account?

Considering the case of nootropic consumption may advance the discussion about interior and public values of medicine. Statistical evidence in medicine is based on belief in universality of biomedical knowledge, while practices of nootropic use vary from country to country and region to region. For instance, phenibut was designed in USSR as anxiolytics and now is widely used over-the counter as well as on prescription in Russia and Eastern Europe. It is used to treat anxiety disorder and insomnia and also to enhance ability to concentrate. In the Western Europe and the USA this substance isn't approved by healthcare regulators (like FDA) but it is available via on-line shops. In the Western countries the substance is used for recreation, not for treatment due to its expected ability to suppress the information noise.

In Russia doctors-supporters of evidence-based medicine interpret a lack of randomized control trials as an argument to consider phenibut a fake drug. On the

other hand, a few clinical cases of overdose and dependence during non-therapeutic use of the substance are available on PubMed. This fact may confirm that substance may influence human physiology beyond placebo effect.

So there is a lack of evidence concerning substance that is not prohibited and widely used in healthcare and for enhancement and recreation goals. No expert opinion and no professional assessment are available for non-therapeutic users of the substance. But the lack of information approved by medical professionals about the risks and a safe dose of the substance can lead to significant harm to non-therapeutic users of enhancements (dependence, overdose).

There is a public request for approved rules of nootropics use beyond results of randomized control trials, that are considered to be interior scientific affairs. Nootropic users are already involved in practices of consumption and they can't find any information about safety of these substances, while the only source of expert opinion about efficacy of performance enhancers is a WADA list of prohibited substances. Doping is considered to be effective. But specific expert board may satisfy the public request for professionally approved information concerning at least safety and rules of consumption of widely used enhancements.

The research is supported by Russian Science Foundation, project 15-18-30057.

---

## **Geriatric long-term facilities : uses and misuses of justice**

Session 1  
Room 1

Marta Spranzi

University of Versailles St-Quentin-en-Yvelines; Center for clinical ethics, Cochin Hospital, Paris (France)

As Paul Ricoeur writes : “The idea of justice is nothing else but the the idea of the good as it concerns others”. Drawing on the results of a clinical ethics empirical ethics study on relational difficulties in long-term geriatric facilities, I shall argue that beneficence often depends on larger conceptions of justice and equality.

I will explore two senses in which the principle of justice is used and misused in these contexts in order to regulate the relations among all concerned parties : patients, nurses and family members.

First, HCP often use an argument from strict equality (“everybody is housed under the same banner”) in order to refuse to respond, or give in, to what they perceive as special requests from patients and family members. Stemming from a legitimate sense of justice, this attitude often verges on a form of unjustified retributive justice: patients who held important positions when they were young and healthy are explicitly reminded that they have lost all those privileges now, by being denied what they need. The relations are all the more tense that patients and/or family members exercise their power and former position in society in order to treat HCP as subordinates.

Second, whereas justice involves impartiality and a certain distance, a misconceived sense justice can prevent the expression of what HCP themselves perceive as their vocation: furthering interpersonal relationships with each individual patient.

In the conclusion, I will hint at some positive ways in which justice can be understood and implemented in geriatric facilities, in order to improve the well-being of all concerned parties.

---

## **The effectiveness of computer-based learning (CBL) and classroom lecture as teaching method of bioethics in medical school: A comparison study**

Yoyo Suhoyo, Ova Emilia & Tridjoko Hadiano  
Faculty of Medicine, Universitas Gadjah Mada, Indonesia

**Background.** Computer-based learning (CBL) refers to a computer-assisted teaching methods in the process of learning. CBL is mostly applied in student-centered active self-study. In CBL, teaching materials, vignettes (written or motion picture), and learning resources can be put into optical storage device or such, e.g. compact disc (CD), thus giving more portability for the students. The effectiveness of CBL as a method in teaching bioethics can be measured from the accomplishment of learning objectives and from the students' learning motivation level. However, the result of interactive CD application in CBL is not yet known. And as the traditional method in teaching bioethics is by classroom lecture, this will be a good "control" for the CBL. **Objective.** To compare the effectiveness of the CBL to the classroom lecture in the teaching of the principles of bioethics.

**Methods.** This is an experimental study, measuring: (1) the bioethics knowledge, measured before and after the intervention, and (2) students learning motivation, measured by Motivated Strategies for Learning Questionnaire (MSLQ). The subjects are all medical students of Universitas Gadjah Mada, Indonesia from the 1st semester. They were randomly assigned into two groups: (1) CBL and (2) lecture group. The data acquired were analyzed with Wilcoxon's rank-signed, Mann-Whitney, and Spearman's rank correlation tests

**Result.** (1) There was a significant increase in knowledge in the lecture group; however the CBL group did not show any significant difference. (2) Both group showed significant increases in learning motivation. (3) The lecture method was significantly better than CBL in increasing knowledge and students' motivation in learning. (4) There is no significant correlation between gender, computer experience and learning style and the increase in knowledge, as well as students' motivation in learning.

**Conclusion.** Classroom lecture is more effective in increasing the knowledge and the learning motivation of the students in the teaching of the principle of bioethics.

---

## Values in conflict during the decision making process surrounding admission to intensive care – Ethnographic study in six British hospitals

Session 3  
Room 4

Mia Svantesson-Sandberg<sup>1,2</sup>, Frances Griffiths<sup>1</sup>, Chris Bassford<sup>1</sup> & Anne Slowther<sup>1</sup>  
on behalf of the ICU-decision making study team

<sup>1</sup>University of Warwick, UK, <sup>2</sup> Örebro University, Sweden

**Objective.** Approximately one in five of all people admitted to an intensive care unit (ICU) do not survive to go home, and for those that do survive, many continue to have serious problems. Given the burdens of therapy on an intensive care unit and the limited prognosis for many critically ill patients, admission to an ICU bed will not be in the best interests of all patients. Most patients considered for ICU admission lack capacity to make decisions and clinicians must therefore make difficult ethical judgements about balancing the benefits of ICU with the burdens of care. There is no agreed process for deciding who should be admitted to ICU and little is known how these decisions are made.

Intensivists often experience decisions as complex. They involve ethical conflicts that may not be recognised. Thus, there is a need to capture ethical conflicts in the reality of the decision-making process. We report on a qualitative study that is part of a larger project exploring how these decisions are made and what influences them. This will feed into the development of a decision-support framework for ICU clinicians and clinicians referring patients to intensive care.

**Aim.** To describe explicit and implicit ethical conflicts present in the process of deciding whether or not a patient is admitted to intensive care.

**Method.** Focused ethnographic field study of 55 decision events, including observations of the patient situations and 143 semi-structured interviews with doctors, outreach nurses, families and patients involved. Setting: six British hospitals with a consecutive sampling of referrals for ICU-admission. We used an ethical interpretative framework for the analysis of interview transcripts and field notes, defining ethics in a broad sense; encompassing principle based ethics as well as relational oriented ethics.

**Results.** The ethical conflicts and questions included: Should all referrals be respected? Should a patient in severe physical and emotional distress be expected to give answers about treatment decisions? What extent of patient suffering is acceptable to allow the process decision-making? Should the threshold for admission be influenced by the availability of ICU beds? Is being a sole decision-maker ethically justifiable? How can we allow for differing professional perspectives and judgement while ensuring fairness to all patients? Whose responsibility is it to break bad news to patient and family? Should the ICU-team be responsible for the safety of a patient assessed as too well for admission? Should the ICU-team initiate end-of-life planning for a patient assessed as too ill for admission?

**Conclusion.** Our preliminary findings suggest decision-making surrounding admission to ICU is laden with ethical conflicts that go beyond weighing burdens and benefits of treatment. These conflicts are variably acknowledged by the clinicians involved, yet influence the process of decision-making. Complex decisions might in

fact imply ethical dilemmas, meaning both admission and non-admission might be wrong or both right. This makes the quality of the process even more important.

---

Session 1  
Room 4

## Work, health and disability: capability and a physician's perspective

Jacques Tamin

Centre for Social Ethics and Policy, School of Law, University of Manchester

The UK Government has stated: "There is a strong moral, social and economic case for supporting disabled people and those with health conditions to work, thus enabling people to lead fulfilling working lives"<sup>1</sup>. Furthermore, it is said that health may have special moral importance<sup>2</sup>, that "work is good for health"<sup>3</sup>, and that "the relationship between employment and health is close, enduring and multi-dimensional"<sup>4</sup>. Although it may be desirable for individuals to be in employment to improve their health, there is also a danger that those who are not able to work become stigmatised<sup>5</sup>. Encouraging individuals to be at work can be beneficial, but it also raises questions such as: Do the socially disadvantaged have access to opportunities to improve their health? Is there access to health-enhancing "good" work?

Lifestyle factors further contribute to some chronic conditions (such as obesity and cardiac disease) which can affect the ability to work. It has been said that "individuals have a fundamental personal responsibility to maintain their own health"<sup>6</sup>. In this context, responsabilisation then appears to go beyond the expectation of individuals pursuing a healthy lifestyle, to placing the onus of staying healthy enough to work on the individual. However, is there fairness of opportunity for all individuals to keep themselves healthy? Do employers have a responsibility to make their workplaces health-maintaining and health-promoting?<sup>7</sup>

This paper aims to contribute to the wider discourse on social determinants of health, particularly, what health justice<sup>8</sup> might mean when one is unable to work through ill-health or disability. The "capabilities approach"<sup>9</sup> as a theory of justice will be used. In this way, I will use insights from the area of 'social justice' to illuminate questions that are traditionally seen as questions of 'medical ethics'.

In conclusion, sickness absence is a serious problem, with consequences to the health of individuals and society, and a huge financial burden to employers and government. However, "tackling" this problem should be done in fair and ethical ways, which will be discussed in this paper.

<sup>1</sup>The Government's Response to Dame Carol Black's Review of the health of Britain's working age population, *Improving health and work: Changing lives*. London:2008, p.6.

<sup>2</sup>See for example, Daniels N. *Just health: Meeting health needs fairly*, 2008. Cambridge University Press.

<sup>3</sup>Ref(2), p.22.

<sup>4</sup>The Marmot Review, *Fair Society, Health Lives, Strategic Review of Health Inequalities in England post-2010*, 2010, at p.69. <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

<sup>5</sup>The government acknowledges this: “We need a health and welfare system that recognises that – one that offers work for all those who can, help for those who could and care for those who can’t”, at <https://www.gov.uk/government/consultations/work-health-and-disability-improving-lives/work-health-and-disability-green-paper-improving-lives>, p.3.

<sup>6</sup>Dame Carol Black Report, *Working for a healthier tomorrow*. London:2008, p.99.

<sup>7</sup>For example, Faculty of Public Health, *Creating a healthy workplace*, 2006, [http://www.fph.org.uk/uploads/r%20healthy\\_workplaces.pdf](http://www.fph.org.uk/uploads/r%20healthy_workplaces.pdf)

<sup>8</sup>Venkatapuram S. *Health Justice*. Cambridge:2011.

<sup>9</sup>For example, Sen A., *The Idea of Justice*. London:2010; and Nussbaum M.C., *Creating capabilities: The human development approach*. Harvard University Press: 2013.

---

## HIV Written Informed Consent: Time to Review the Italian Standard?

Session 2  
Room 1

Jacopo Testa<sup>1</sup>, Alessandra Gasparetto<sup>1</sup>, Elena Montaguti<sup>1</sup>, Federico Nicoli<sup>1,2</sup> & Mario Picozzi<sup>1</sup>

<sup>1</sup>Biotechnologies and Life Sciences Department, Insubria University, Varese, Italy;

<sup>2</sup>Clinical Ethics Service “Domus Salutis” Clinic, Teresa Camplani Foundation, Brescia, Italy

HIV-infection is responsible for up to 39 million deaths in history and approximately 36.7 million people are now living with HIV globally; sexual transmission is still the main cause of infection. European Countries (EC) reported HIV-testing rates of about 50% and relatively few countries have testing data for key populations—for example men who have sex with men (MSM) or people who inject drugs (PWID).

In Europe most of the countries have a post-test access to treatment as well as prevention services and almost 70% have a correct informed consent procedure for a voluntary and confidential testing. In the Italian legislation, HIV testing requires written informed consent and pre and post-test counselling. Europe is at a crossroad regarding the development of a coherent, comprehensive HIV testing strategy.

In the beginning, HIV was exceptionally stigmatized and some EC believed that mandatory testing of certain social groups would have been appropriate. In Europe, HIV-testing had to be conducted differently from other blood tests: it was required to be voluntary, confidential and a preferably written informed consent form.

In the Italian legislation, HIV-testing mandates written informed consent as well as pre- and post-test counselling. This procedure was mainly established to protect individual rights at risk of being jeopardized. In the 90’s, receiving the diagnosis of HIV-infection was indeed perceived as a “death penalty”. With Highly Active Anti Retroviral Therapy (HAART) HIV-infection can now be compared to other sexually transmitted infections. We intend to investigate whether it is appropriate to review the Italian standard written procedure to obtain informed consent. With the introduction of HAART and new drugs, most of the HIV-infected people can

now have a normal life and an increased life expectancy, largely comparable with their HIV-negative peers.

It has been argued that large number of people receiving late HIV diagnosis along with recognized barriers in obtaining informed consent in a written form may justify to extend even to HIV-testing the standard criteria which govern authorization for routine health care treatments. In relation to this, revised recommendations for HIV-testing from the Centers for Disease Control and Prevention (2006) as well as the European Guideline on HIV-testing (2014) suggest that a general verbal information, as per normal routine care, provided to subjects with suspected clinical signs and pregnant women, can replace a written consent form; this seems to lead to increased early HIV infections diagnoses. In any case, the explicit consent of the person must always be obtained.

In order to make it possible, a great deal of efforts must be made to implement both large educational programs which concern HIV-related risky behaviours and public awareness campaigns aimed at removing HIV social stigma. Fear of being identified as positive for HIV may discourage a person from getting tested, accessing medical services and obtaining medications. Even though easier HIV-testing procedures may be beneficial to individual patients as well as to public healthcare, considerable attention must be paid to frail people such as migrants and PWID, who may be at risk of becoming subject to uncontrolled screening practices.

---

## **Social Responsibility and Health from Six Religious Perspectives**

Session 1  
Room 3

Joseph Tham

School of Bioethics, Rome, Italy)

This is a report of a workshop of bioethics scholars from six different religions that took place in Mexico City in 2014. The topic for this encounter was to analyze Article 14 of the UNESCO Declaration on Bioethics and Human Rights concerning “Social Responsibility and Health.” This was part of an ongoing project of inter-religious dialogue of the project of Bioethics, Multiculturalism and Religion of the UNESCO Chair in Bioethics and Human Rights. Speakers were assigned to write main papers from the perspectives of Buddhism, Christianity, Confucianism, Hinduism, Islam and Judaism, along with responses, one within the same faith tradition and the other from a different one. Each of the contributors were asked to explore Art.14§1 and §2a of the Declaration, focusing on the issues of justice, access and social responsibility in healthcare, according to the different aforementioned religious perspectives. Furthermore, they were asked to delineate how religion has contributed in improving the health of the society.

Article 14 states:

1. The promotion of health and social development for their people is a central purpose of governments that all sectors of society share.

2. Taking into account that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition, progress in science and technology should advance:
  - a access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good;

In this encounter, we saw how the principle of social responsibility is understood according to different religious traditions: Judaism conceives it as universal equality; Islam as duty to God; Christianity as neighbourly love; Confucianism as duty towards the family; Hinduism as a right balance of different duties; and Buddhism as active compassion. The report will also cover the areas of convergence, differences and challenges faced by these religions and cultures. They regard the relationship between state and religion in an ever secularized world; the relationship between health and salvation; the question of egalitarian distribution; and the relation between responsibility and rights.

---

## **On Double Helix of Life Technologization: Co-production of Knowledge, Technologies and Values**

Session 2  
Room 2

Pavel Tishchenko & Olga Popova

Institute of Philosophy, The Russian Academy of Sciences, Moscow

Medicalization of society in modern situation is upgraded by swift development of human bioenhancement technologies. Life medical improvement and technological betterment could be interpreted as phenomenon of technoscience.

Due to the Russian philosopher B. G. Yudin, technoscience is constructed by two contours – internal and external. The external contour is constituted by social interactions between science, business and society. The internal - by laboratories (B. Latour) - multidimensional nets of relationships between science and technology in conducting experiments, development of instruments (e.g. visualization tools), etc. Coordinated activity of the internal and the external contours of technoscience is provided by a synergy of regulatory principles of truth, goodness (good life in just institutions – P. Ricoeur) and usefulness. The case of synthetic biology will be used for demonstration of internal and external technologization contours.

Technologization is understood as a transition from research techniques to systematic use of technologies. The meaning of technique here refers to methods and/or a means of action, based on inalienable from the subject personal knowledge (M. Polanyi). The technology is a method and/or a mean of action, founded on transferable, intersubjective knowledge. In general, technologization is a process of transformation of scientific craftsmanship into coordinated knowledge production of computerized machines. In this sense we can say that the “The Human Genome Project” was started in the 90s of the 20th century in scientific “manufactories”, and ended in automated scientific “factories”. The transition from research techniques

to technologies presents a significant feature of synthetic biology. Standardization of materials and technological procedures provides an opportunity for scientific outsourcing – possibility of distribution of research tasks between different scientific organizations for solution of a common problem.

In the internal contour of synthetic biology, artificial biological cells (biological life forms) are constructed. In the external contour - social "cells" (social life forms) are designed through systemic use of bioethics (Nowotny, Testa).

Biotechnological innovations at the level of manipulation of invisible for human eyes cellular and sub-cellular structures could provoke (against the will of developers), multiple underlying social processes that generate the most diverse and unexpected consequences. The task of bioethics (as technology of goodness pursuit) lies in pro-active (anticipatory) diagnosis, assessment and management of risks associated with the development and implementation of biotechnological innovations: not only risks with regard to human health or ecological well-being, but also those ones which are inherently social and human (moral, anthropological, legal, political, economic, etc). In solving these problems, bioethics in collaboration (co-production) with biomedical sciences and technologies, plays its' role in ordering of social relations, in the same way as science brings order into the natural world.

Research was supported by the National Science Foundation under Grant Num. 15-18-30057

---

## **El paper dels coordinadors d'Equips d'Atenció Primària: conflicte de lleialtat?**

Session 1  
Room 6

Gemma Torrell Vallespín

Introducció. La realitat de l'atenció primària (AP) a Catalunya és heterogènea. Existeixen diferents proveïdors de salut, essent el majoritari l'Institut Català de Salut. Les estructures de direcció d'aquests proveïdors són diferents, en tant que un major volum d'Equips d'Atenció Primària (EAP) que en depenguin fan que l'estructura hagi de ser més robusta i per tant, tingui més actors intermedis, entre els professionals i les persones que prenen la major part de decisions.

El Servei Català de la Salut és l'entitat que s'encarrega de garantir "les prestacions sanitàries per tal que els recursos sanitaris, econòmics i humans estiguin al servei dels ciutadans amb uns criteris d'equitat, qualitat i eficiència". Aquesta, seguint la línia estratègica que marca el Pla de Salut quinquennal dissenyat pel Departament de Salut, signa un acord de gestió amb cada proveïdor de forma anual, que conté diferents objectius a complir i lligats al territori, a la mateixa línia assistencial (hospitalària, atenció primària, p.ex) i particulars (EAP), vinculat a una dotació econòmica variable segons la consecució dels mateixos. Aquest acord arriba als directors d'EAP per tal de treballar-los durant l'any. Aquests objectius no s'acompanyen d'una argumentació científica al darrera que els hi doni validesa.

La responsabilitat que s'atorga als directors de centre és elevada però el seu poder fàctic és fictici. El seu marge d'acció és limitat en tant que la seva lleialtat es veu supeditada a l'exigència econòmica d'obtenir bons resultats anuals (lleialtat a la empresa) que no sempre implica benefici pel pacient (tot i que sí si entenem

que els diners que s'aconsegueixen amb l'acord, repercuteixen en el benestar de l'equip i de retruc en el benestar del pacient) i contraposada a la lleialtat amb l'equip al què representa i en última instància, al pacient. Si la lleialtat és al costat del pacient és una responsabilitat del coordinador d'EAP transmetre i denunciar aquelles situacions o objectius que posin en perill el benestar del pacient; que puguin traslladar el focus d'atenció dels professionals de l'atenció al pacient (a l'objectiu i al seu registre); que afectin als valors intrínsecs que defineixen l'AP (longitudinalitat, accessibilitat, integralitat, coordinació); que atemptin contra les tasques bàsiques del metge de família (atenció domiciliària, atenció al final de la vida, atenció al pacient crònic complex). Per altra banda, la por a represàlies (perdre el rol de direcció, p.ex.) pot dinamitar la possibilitat de rebel·lar-se contra l'autoritat.

Si bé existeixen situacions micro que es traslladen com a responsabilitat de la institució quan probablement són responsabilitat del centre i de la gestió del coordinador/director (organització de les agendes), aquestes estan inscrites en un entorn que és macro que les intensifica (precarització laboral, falta de pediatres, no cobertura de les substitucions, pèrdua de professionals i de pressupost, etc) i que depèn, en certa mesura, però no en tota, de l'administració i la institució a la què es pertany (que ha de distribuir de forma justa els recursos limitats). L'alienació dels professionals provocada per la col·lisió d'aquests dos entorns – macro i micro -, pot impossibilitar l'abstracció de la feina diària i impedir tenir presents els valors de la professió (i defensar-los).

Conclusions. El càrrec de director d'EAP implica en la seva essència un component de justícia social, en tant que la seva lleialtat ha de continuar estant amb l'equip al què representa i amb el pacient a l'hora de gestionar els recursos. L'entorn actual evidencia la necessitat de direccions que siguin conscients del seu rol i de la seva posició quant a garants dels valors de l'AP. És necessari iniciar un debat ètic sobre el rol dels directors d'EAP.

---

## **Demencia severa: hacia un enfoque terapéutico justo.**

Ainhoa Unzurrunzaga Diaz, Esther Martinez Becerro & Raquel Jaso Tejera  
Osakidetza - Servicio Vasco de Salud (Basque Health Service)

Session 4  
Room 7

Introducción. La demencia es una enfermedad de prevalencia creciente en Occidente. Presenta un curso progresivo y en sus etapas finales, la dependencia y la inactividad son totales, el deterioro cognitivo es severo. Su importante impacto sobre el gasto sociosanitario lo convierte en uno de los grandes retos de la salud pública. La neumonía es la causa principal de muerte en pacientes con demencia avanzada.

Material y métodos. Realizamos un estudio retrospectivo que entre otros objetivos pretende analizar el tratamiento dispensado a pacientes con demencia severa y con neumonía que ingresaron en nuestro servicio entre el 1 de marzo del 2013 y 31 de julio 2014. Se revisan historias clínicas de 51 pacientes.

Resultados. El 100% de los pacientes analizados en este estudio han sido tratados con intención curativa. El 100% es tratado con antibióticos, el 53%, con antibióticos de última generación, el 94% han recibido sueroterapia, se realizaron 4 extracciones

sanguíneas de media, en mas de la mitad de los pacientes se coloco una sonda urinaria, en un 7% una sonda nasogastrica.

Discusión. El escaso beneficio que esta actitud terapéutica aporta a esta población, su elevado coste económico en un sistema de salud de recursos limitados y sometido a continuos recortes, y su elevado coste ecológico, plantean la necesidad de reflexionar sobre el enfoque terapéutico más adecuado a adoptar desde el punto de vista ético. Con respecto al coste ecológico los antibióticos pueden considerarse un “recurso escaso” y su utilización en estos enfermos terminales puede dejar sin tratamiento a pacientes futuros que podrían verse privados del mismo.

---

Session 1  
Room 6

## **Impacte del Programa Comunitari al SRC Granollers Benito Menni en la integració social dels usuaris**

Mònica Alonso Valcárcel, Olga Ayza Pérez, Marc Garcés Domingo, Ignasi Garcia Naranjo, Belén Gías Gil, Queralt Torres Cayuelas & Lourdes Tudela Cantallops

Les persones amb trastorn mental greu (TMG) presenten moltes dificultats en les habilitats socials, fet que dificulta la seva integració i participació en la societat. Això afecta directament en la manca de rols socials, disminuint l'autoestima i el sentiment de pertinença. És per això que la intervenció a nivell social i comunitària és imprescindible en la rehabilitació psicosocial d'aquestes persones.

El Servei de Rehabilitació Comunitària de Granollers (SRCG) és un servei de la xarxa de salut mental situat a la comarca del Vallès Oriental (Barcelona). Atén a persones amb TMG d'edats compreses dels 18 als 65 anys. Té com a funció principal la integració social i el increment de la autonomia personal d'aquestes persones.

La metodologia del SRCG és realitza de forma individual mitjançant seguiments multidisciplinaris (Psicologia, Teràpia Ocupacional i/o Educació Social), i grupal.

La intervenció grupal s'emmarca dins de 4 programes:

1. Programa Funcional d'Activitats Rehabilitadores: Tracta de donar resposta específica a les necessitats corresponents a la funció de rehabilitació psicosocial, modificant i reeducant les discapacitats que presenten i incrementant les habilitats i recursos d'afrontament.
2. Programa d'Atenció a les Famílies: L'objectiu d'aquest programa és facilitar a les famílies la informació, suport i orientació necessària en cada cas per a un correcte afrontament de la problemàtica, afavorint el conjunt de la intervenció rehabilitadora realitzada amb l'usuari.
3. Programa de mitja i llarga estada: Adreçat a usuaris del SRCG amb anys d'evolució del trastorn, baixa funcionalitat, inadequada xarxa de suport i/o alt risc de recaiguda. Els objectius d'aquest programa són mantenir l'autonomia, prevenir recaigudes i vincular als usuaris a mig-llarg termini a recursos comunitaris.
4. Programa d'Integració Comunitària

L'objectiu del programa és facilitar la (re)inserció dels usuaris del SRCG en la comunitat.

Es realitzen dos tipus d'intervenció en funció de la interacció amb l'entorn: Activitats realitzades en la comunitat; on s'utilitzen espais i recursos que ofereix el municipi (esports, ràdio, aquagym, ...); Activitats realitzades amb i per la comunitat; on col·laborem amb diferents entitats per a cobrir demandes socials; voluntariats (Escoles públiques, Protectora d'animals, residència geriàtrica, biblioteques, ONG's,...)

A través d'aquest programa, els usuaris tenen la oportunitat de conèixer els diferents recursos de la zona, explorar nous interessos, recuperar habilitats socials i afavorir la seva participació com a ciutadà de ple dret.

El nostre objectiu és presentar l'impacte del programa comunitari en la integració social dels nostres usuaris i com aquest facilita la seva vinculació als diferents recursos comunitaris. Revisarem la història ocupacional i social abans i després de la seva participació en el programa comunitari emfatitzant si abans d'iniciar el programa feien ús de recursos i quins eren, i si després d'aquesta intervenció han augmentat la seva integració comunitària. També, especificarem si aquests recursos es troben dins de la xarxa de salut mental o són recursos ja existents a la societat. Tot això basant-nos en dades recollides entre els anys 2015 i 2016.

---

## **Dealing with a request for assisted suicide in psychiatry: a training module for psychiatrists in the Netherlands.**

Session 3  
Room 5

Laura van Melle, Eric Ettema, Yolande Voskes, Albert Christiaan Molewijk & Guy Widdershoven

VU University medical center

**Introduction.** In recent years, increasing attention has been paid to requests for physician assisted suicide (PAS) by psychiatric patients. Many psychiatrists struggle with the ethical complexity of dealing with such a request and feel insecure about how to deal with a psychiatric patient's serious wish to die. To assist psychiatrists in dealing with these issues, the VU University medical center in cooperation with the Dutch Psychiatric Association developed a training module for psychiatrists and residents. **Objective.** The aim of this presentation is to present a training module which supports psychiatrists in dealing with conflicting values around requests for physician assisted suicide of psychiatric patients in the Netherlands.

**Methods.** The module was constructed by means of dialogical research, in which the moral considerations of stakeholders involved in dealing with requests for physician assisted suicide were explored. Psychiatrists with experience in dealing with such a request were interviewed. In focus and dialogue groups, the findings were related to the experiences of nurses, social workers/spiritual counselors and family members. The results were analyzed and didactically elaborated in a training module.

**Results.** Stakeholders consider it particularly important that care professionals become aware of their own values, norms and limitations with regard to PAS. In addition, they emphasize the importance of being open to discuss requests from

psychiatric patients for PAS. Other ethical considerations regard the role of the family, the added value of multidisciplinary cooperation and the quest for dignified dying. The module contains short case studies that are built around the following four themes: Awareness, Quality criteria, Cooperation and Dying with dignity. The assignments in the module focus on individual and collective reflection on a wide range of ethical issues concerning the request for assisted suicide.

Discussion. During the presentation we will discuss in an interactive way the various ethical issues experienced by psychiatrists in dealing with a request for assisted suicide. Careful assessment of a request for PAS not only requires application of the procedures but also reflection on the ethical complexity of PAS in psychiatry. Central to the assessment is that the psychiatrist does justice to the various and often conflicting values within a particular case. We expect that the introduction of a training module for psychiatrists will improve the care for patients with a serious wish to die.

Session 4  
Room 3

---

## **Institutional space for multi-perspective decision-making: what are the challenges?**

I. van Nistelrooij<sup>1</sup> & H. Kohlen<sup>2</sup>

<sup>1</sup>University of Humanistic Studies, Utrecht, The Netherlands, <sup>2</sup>  
Philosophical-Theological University, Vallendar, Germany

Over the past decades a development has taken place that has first transferred and then distributed responsibilities for decision making in (health) care practice. First we moved from a paternalistic practice ('doctor knows best') to an emphasis on autonomy ('patient knows best'). From there we moved to an increasing sharing of responsibilities ('shared decision making'). However, the image that only two persons (doctor and patient) are involved in caring practices and decision making, many times fails to represent the actual situation (Van Nistelrooij, Visse, Spekkink & De Lange, in press): most forms of (health) care are forms of cooperation.

First, cooperation takes place in professional teams. Team deliberation models have been developed, for instance for ethical case deliberation, which help to improve relationships among team members, foster mutual openness and understanding for different perspectives (Janssens, Van Zadelhoff, Van Loo, Widdershoven, Molewijk, 2015). Nevertheless, in this professional cooperative reflection the aims of a non-hierarchical, democratic exchange of arguments are not always reached. Hierarchies are reflected in the positioning at the table, in what is planned in the agenda of the meeting, and in what arguments count and are rejected or neglected (Kohlen 2009).

The second form of cooperation challenges the classic distinction between the roles and positions of caregiver and care-receiver. Especially since formerly acute and life-threatening illnesses have increasingly become chronic (Pols 2013), patients and other care-receivers are taking care of themselves for a large part of their everyday life, often together with their partners and/or family members. They develop knowledge and expertise that may overlap, but also differ from the expertise of doctors and nurses. This expertise, from 'informal' perspectives, challenges the existing forms of ethical deliberation and decision-making too (Van Nistelrooij et al, 2017).

These forms of cooperation require a search for multi-perspective forms of ethical deliberation and decision-making. In order to reach a well-argued decision, the challenge lies in multi-perspectiveness. The central question might be: ‘Have we allowed and enabled everybody who has relevant expertise to express their knowledge in a multi-perspective process of determining good care in this particular situation?’

This requires institutions that create space for deliberation between those who are involved in a concrete caring situation. Space that allows for non-professional, perhaps also non-verbal, non-argumentative, expressions of ‘the good’, that shed a light on the situation from multiple perspectives.

We aim to do research on these kinds of deliberations. Some experimental forms have already been developed, using theatrical forms, but others need to be developed further, for instance those who are using art. A new research project aims to develop multi-perspectiveness, drawing upon a program developed and implemented in Berlin and existing forms of deliberation in the Netherlands.

The presentation aims to discuss the contents and methods of the research project in order to receive input for it.

---

## **Nanomedicine and human health: when big questions arise from small technologies.**

Vittoria Viganò & Mario Picozzi

Center for Clinical Ethics, Insubria University, Italy

Session 2  
Room 1

The astonishing development of nanotechnologies during the last decades made a broad range of applications possible in almost every sector of our life including engineering, agri-food industry, textile sector, military field and pharmacology also. In fact several food packaging, clothes, cosmetics, electronic devices and even drugs already contain nanoparticles therefore everybody is steadily exposed nowadays.

Nanomedicine, namely the application of nanotechnology to medicine, aims to improve diagnosis, therapies and thus the prognosis of patients, with a reduction of time and costs. Nanomedicine is also leading to a revolutionary approach to the disease management known as “theranostic”: the possibility to diagnose and treat the patient at the same time with a single drug administration.

Despite encouraging results and interesting perspectives, nanomedicine applications could exacerbate serious issues, such as: resource allocation, social inequalities in health, integrity in research, medicalization of life, public involvement, environmental impact, human enhancement and human safety.

Consequently, given the pervasiveness and uncertainty of these technologies, it is now imperative to question current research protocols and laws from a moral point of view. Our first goal is to analyse the current literature and to draw a comprehensive picture of the state of art regarding ethical reflection on nanomedicine, to expose crucial issues in research, development and marketing of novel drugs containing nanocomponents. Our second goal is to set an ethical reflection based on the core principles of beneficence, non-maleficence, justice and autonomy. We thus want to verify if nanomedicine is taking into account those principles or not, with the

certainty that ethics can promote a scientific development respectful of human health and dignity.

---

Session 2  
Room 1

## Why cannot Western individualism be comprehensive? Vaccine refusal debates in Turkey

Mustafa Volkan Kavas<sup>12</sup>

<sup>1</sup>Ankara University Faculty of Medicine, Department of History of Medicine and Ethics,

<sup>2</sup>VUmc Amsterdam, Department of Medical Humanities

In 2015 a Turkish couple filed a lawsuit to the Supreme Court in request for their child to be exempt from the mandatory Broadened Vaccination Program. The court sentenced that “since vaccination is mandatory to protect both the child’s and the society’s health in the future, (...) approving the request basing only on the parents’ dissent was found contrary to the law and procedures.” The Minister of Health of that time, Mehmet Müezzinoğlu, stated that a juridical regulation would be made soon and added “in any case persons come before the right to refuse vaccination when the public health is at stake”. The family appealed the decision to the Constitutional Court in June 2016. The jury concluded that “vaccinating a child pursuant to healthcare measures without the consent of parents is against both the constitution’s 17th clause regulating a person’s inviolability and substantive and moral integrity, and the 13th clause on the limitation of basic rights and freedoms.” In November 2016 the current Minister of Health, Recep Akdağ, mentioned that he disagreed with the Court’s decision, but there was no need for a new regulation addressing such personal requests.

As exemplified here, there has been growing confusion about vaccination refusal in Turkey. Although worries in people’s minds are various, the conflict is simple: Should we accept personal requests for refusing vaccination, even though it is against the efforts to improve social immunization?

However, the main question of this study is something else: How would somebody who adopts individualism lying in the heart of Western morality answer this question? As might be expected, with utmost confidence she would say “even if with good will or for beneficence, you should not apply anything on a person unless she consents for it.” This motto is based on the human rights conceptualization which is claimed to cover not just some people from a particular culture, but all humans. The idea that personal freedom surpasses all kinds of positive rights is believed to be universally comprehensive. However, if you determine your vaccination policies according to this principle in Turkey, it would be impossible to sustain a certain level of social immunization, let alone to improve it.

Individualistic ideals are sometimes dysfunctional against serious problems some societies face. We will discuss reasons underlying this inference in the context of ongoing debates on vaccination refusal in Turkey. Although Turkey seems to have subjective conditions, hereby the conflict is profoundly related with three interwoven dimensions valid for all human societies to which the individualism approach is blind: 1) Ideas are spread and defended by collective agents who are more powerful than individual agents. In this situation, individuals are ontologically vulnerable against

collective agents, unless they are protected by them. 2) Vaccines have been turned to commodities in the global market run by powerful organizational forces. 3) An individual is a social entity, and therefore, is determined by ideological and material dynamics effective in a society, for instance, in terms of her understanding of health and her health status.

---

## **Autonomy and coercion in psychiatry, a care ethics perspective**

Yolande Voskes & Guy Widdershoven

Session 3  
Room 6

In psychiatry, like in somatic medicine, patients ideally agree with the treatment proposal of the physician. Yet, psychiatric patients, more than other groups of patients, often refuse treatment. Not too long ago, attempts of psychiatric patients to avoid treatment were obstructed by physicians who deemed the patients incompetent or dangerous and treated them against their will. In reaction to medical paternalism, patient rights were put forward, especially the right to refuse treatment. This right was grounded in the principle of respect for autonomy, and the requirement of informed consent. If the patient does not cooperate, the physician has to refrain from intervening, until danger occurs. In case of a refusing patient, the patient's freedom to decide for himself should be respected, until the situation becomes dangerous. At that moment, the physician may (and even has to) intervene, and force the patient to undergo measures aimed at removing the danger, either by putting the patient in a safe environment (involuntary admittance to a psychiatric hospital, or putting the patient in a seclusion room), or by calming down the patient with enforced medication. Consequently, the patient loses his freedom, and is confronted with a coercive measure. The situation drastically changes from one of non-intervention, leaving the patient the freedom to do what he or she likes, into one of full intervention, without any freedom left.

In this presentation we will reflect on a case and we will argue that a different view on patient autonomy is needed, which does not focus on the right to refuse treatment, but on the ability to develop a way of dealing with one's situation. From this alternative view on autonomy, intervention is not a priori suspect, but may support the patient in finding new ways of leading a meaningful life. We will show that a care ethics perspective, which emphasizes relations of concern and responsibility, may enable physicians to go beyond the dichotomy between letting the patient totally free on the one hand, and using force and coercion on the other hand.

---

# **The role of scientific experts and their perceived responsibility towards society. A qualitative interview study with natural scientists**

Session 4  
Room 5

S. Wäscher, A. Deplazes Zemp & N. Biller

Andorno Institute of Biomedical Ethics and History of Medicine, University of Zurich

**Background.** Responsibility is a widely used term in many fields of social interaction and in most cases it expresses a normative (moral) demand. When used in such a broad manner, words remain dazzling buzzwords without a clear reference. Aim of this contribution is to shed light on the responsibility attributed to natural scientists.

The literature differentiates between (at least) two levels of responsibility. First, from a very broad perspective everybody who qualifies as an autonomous person is bearer of a general responsibility. Second, from a narrower perspective every person has further responsibilities directly related to the specific roles she or he performs (role responsibility). Scientific responsibility - as a role responsibility - can further be differentiated. First, the aspects of responsibility within the scientific community, which are usually discussed under the term scientific integrity. Second, the aspects of responsibility dealing with the relationship between the scientific community and the rest of society. This contribution concentrates on the latter.

The general perception of science changed during the last decades from a rather detached and autonomous field to an integral part of society. Demands towards science are high, e.g. it shall benefit society by guidance and problem solving. This is supported by various sociological analyses which attribute science with a special and/or over-proportionate relevance for the whole society. Thus, scientists are increasingly expected to situate their research within a society wide (applicable) context. On this basis, it can be assumed that in the same way the role of scientists and their corresponding responsibility has changed during the last decades.

**Methods.** We conducted semi-structured open-ended qualitative expert interviews. Up to the present, we interviewed 13 senior researchers from natural sciences, namely biology, physics, and chemistry. The interviews will be analyzed by means of a grounded theory approach.

**Results.** The overall aim of the empirical investigation is to shed light on the scientist's views regarding their own professional role and corresponding responsibility. Considering contemporary literature, the results will be categorized into different topics helping to enrich the term of scientific responsibility with concrete content. Up to this day, the analysis is still in progress and sturdy results will be presented at the conference. Topics discussed in the interviews, among others, are: responsibility within basic and applied research; dual-use/misuse of scientific research; the relevance of uncertainty for responsibility; public engagement of scientists as a responsibility; interrelated responsibilities between different parts of society; strategies to neglect or avoid responsibility.

**Conclusion.** Among the interview partners' views on their own role as scientists vary and simultaneously show similarities, as does the corresponding responsibility. So far, it can be stated that scientists see themselves as a part of society within society but simultaneously still stick to a rather traditional paradigm in which science

is detached and autonomous from society. This talk concludes with a discussion on this ambiguity in perspectives and gives first ideas of how to cope with them.

---

## **Which health inequalities are unjust? Moving the dialogue between theory and practice forward**

Session 2  
Room 5

Verina Wild

Philosophy Department and Institute of Ethics, History and Theory of Medicine,  
Ludwig-Maximilians-University Munich

Public health interventions often not only seek population health but also health equity. There is a long-standing discussion on how to measure and define health equity and the importance of underlying social determinants of health. Furthermore, the question which health inequalities are actually unjust and should be therefore prioritized has been debated for some years.

This paper will briefly summarize the status quo of the discussion on which health inequalities are unjust. It will refer to Margaret Whitehead's thesis about health inequity, philosophical replies to her thesis and broader normative foundations of health justice. The results of these debates seem to say that as long as there is disagreement on the normative foundations of (health) justice, there cannot be a unanimous answer to the question which health inequalities are unjust. More normative clarity on the underlying foundations is required.

These discussions seem to be rather theoretical, and a unanimous agreement on underlying foundations of (health) justice is no realistic aim. However, on the basis of two case studies the paper will explain the significance of these seemingly theoretical debates for the practical context. The first case is about the WHO No smoking policy that prohibits recruiting staff members who smoke. The second is about health incentive programs that are supposed to reduce obesity.

On the basis of these illustrations the paper will endorse the claim that even if the answer to the question which health inequalities are unjust cannot be unanimously found, better health equity can be achieved if the underlying assumptions about justice are made explicit. Ethics are challenged to continue developing convincing and accessible theories of health justice and to nurture a functioning dialogue with health policy, practice and teaching.

---

Session 4  
Room 2

## **”It is lonely at the top” – exploring ethical challenges of head physicians**

Benjamin Willi, Caroline Brall & Rouven Porz  
Unit for Clinical Ethics, Bern, University Hospital

**Background.** In fast evolving health care systems in the Western world medical staff has to face complex ethical challenges more and more often. Especially head physicians, who are responsible for making ‘right’ decisions, have to deal with various challenges at the same time. In our study, we aim to identify the dimensions which head physicians have to deal with and to evaluate how they cope with these situations and are able to make just decisions.

**Method.** For this study we used a qualitative, semi-structured interview design for interviewing head physicians in a University hospital in Switzerland. The interpretation of the data obtained was based on an open phenomenological approach.

**Results.** According to the interviewed head physicians the most challenging tasks are those involving the management and leadership of their employees like dismissals, difficulties in communication or resource scheduling. A demanding aspect in these situations is loneliness, which most of the interviewed head physician experience in trying to find an appropriate solution for the current challenge. Discussions with peers is normally the preferred way in decision making, but in certain situation this is not possible due to availability or confidentiality.

Session 1  
Room 5

---

## **Promote empathy, not only as an improvement for professional burnout, but a key element in the quality of care**

Oriol Yuguero, Montserrat Esquerda, Joan Viñas, Josep Pifarré & Jorge Soler

**Introduction.** Patient doctor relationship is a fundamental element in the practice of care. The most humanized medicine has taken a very important momentum in recent years, promoting a patient-based medicine. The economic and social situation, with the appearance of cuts in health policies, has led to an increase in the pressure on healthcare professionals. In addition to having less resources and less time to care for their patients.

Burnout is defined as a syndrome in which the professional suffers a wear and tear on his daily work. This results in less professional fulfillment, a depersonalization of the relationship with the professional and an emotional exhaustion.

Empathy is the ability to understand the situation of the person in front of you, and convey that understanding.

**Methods.** Our research with primary care professionals serving a population of more than 100,000 people has shown that elevated levels of empathy are associated with lower burnout. In addition, it has been shown that professionals with greater empathy can achieve improvements in clinical aspects such as the control of Diabetes and Hypertension.

**Results.** It is necessary to promote communication skills in health centers and in health professionals in general that allow efficient communication and empathy

with patients. It should be a priority of the different managers and heads of health institutions.

An empathic attitude towards patients, allows a greater professional development of both doctors and nurses, which significantly reduces their burnout. Low levels of burnout among professionals, improves the work environment of health centers and allows a better interprofessional relationship. In addition, those professionals with greater empathy and less burnout, perform good care registration tasks and obtain better results in health care quality indicators.

Conclusions. To promote an empathic attitude in the health services, has a good answer in improving the professional wear and in obtaining clinical benefits for the patients. Professionals have the opportunity to offer better assistance, and feel better professionals in their day to day.

---

## **Honest intellectual leadership of a scientist in research within the higher education: being ethical, moral and responsible**

Vilma Zydziunaite & Aivaras Anuzis

Vytautas Magnus University, St. Ignatius of Loyola College, Kaunas, Lithuania

Session 4  
Room 5

Background. The society, foundations and other institutions have to have trust, must be able to have trust – be it in the honesty and integrity of academics and research institutions, the critical, fair appraisal and healthy skepticism of reviewers or, finally, that the self-cleansing powers of science actually work. It is important to recognise that the review system has long since reached its limits given the sheer volume it is faced with today. Concern that something might get overlooked is simply increasing. And how do we deal with allegations? Are there errors that are forgivable? Are researchers totally innocent until proved indubitably guilty? Matters have to be weighed up carefully because the consequences for the career and life of the person involved may be irreversible. The accusation of falsification, invention or plagiarism could develop into a crippling instrument of combat, used by every competitor to disqualify others from the race for funding or positions. In order to solve science's honesty problem, however, more than this is required. Honesty is not negotiable in science.

Purpose: to reveal the characteristics of honest intellectual leadership of a scientist in research within the higher education.

Methodology: the study was qualitative descriptive. The theoretical sampling was applied in the study. The sample size was increased until no new insights from the data were generated. The total sample was n=39 scientists from 10 universities and 9 Colleges of Lithuania. The data were collected in the format of semi-structured interviews. The Constructivist Grounded theory (CGT) (Charmaz, 1983, 2005, 2006, 2011, 2012, 2014) as the methodology and the method was applied in the study. CGT focuses on interpretive understandings of meanings, and this version of GT is equal to multiple social realities (Charmaz, 2011). CGT coding is inductive, comparative, interactive, and iterative and then deductive (Charmaz, 2012).

Ethics: ethical approval for research implementation was received from the Board of the Vytautas Magnus University (Lithuania).

Findings. Several categories were extracted from the qualitative data and every category is characterized by its original content:

- Being honest is the core category, with which other categories are interrelated. Scientists accentuate here the seeking for innovativeness in research topics and the scientific production; seeking for clarity in substantiation of scientific ‘truths’; being able to detach the self from personal attitudes within the research.
- Being ethical for scientists mean expressing respect regarding contribution of colleagues; caring for holistic health of research participants within the research study.
- Being moral for scientists is related to perceiving the purpose of research utilization.
- Being responsible by scientists is seen as being morally accountable for research evidence-based information and performing all research stages carefully.

Conclusion: Scientists like to think that they are objective scholars who judge people on merit, the quality of their work, and the nature of their achievements, copious research shows that a lifetime of experience and cultural history shapes everybody of them and their judgements of others. Scientists hold unconscious, implicit assumptions that influence their judgements and interactions with others.

---

## **Retaining for scientist’s reputation within the ethical intellectual leadership in higher education through being open and seeking for quality, and meaningfulness in research**

Session 4  
Room 5

Vilma Zydziumaite & Aivaras Anuzis

Vytautas Magnus University, St. Ignatius of Loyola College, Kaunas, Lithuania

Background. The ethical intellectual leadership focuses on roles, contexts, situations in which ethics and morals are meaningful components. Moral and ethics within the ethical intellectual leadership shift the emphasis from functional higher education school outcomes (effectiveness) to moral purposes such as equity. The ethical intellectual leadership does not care about hierarchy, but focuses on the dynamics of relationship between intellectual leaders (scientists, researchers, scholars) and followers (students, academic and / or non-academic colleagues).

Scientists, research institutions, and government agencies relied solely on a system of self-regulation based on shared ethical principles and generally accepted research practices to ensure integrity in the research process. Among the very basic principles that guide scientists, as well as many other scholars, are those expressed as respect for the integrity of knowledge, collegiality, honesty, objectivity and openness. These principles are at work in the fundamental elements of the scientific method. More particular principles characteristic of specific scientific disciplines influence the methods of observation; the acquisition, storage, management, and

sharing of data; the communication of scientific knowledge and information; and the training of younger scientists.

Purpose: to reveal, what does it mean for scientists the retaining for their reputation within the ethical intellectual leadership in higher education.

Methodology: The theoretical sampling was applied in the study. The total sample was n=39 scientists from 10 universities and 9 Colleges of Lithuania. The data were collected in the format of semi-structured interviews. The Constructivist Grounded theory (CGT) (Charmaz, 2011, 2012, 2014) as the methodology and the method was applied in the study. CGT focuses on interpretive understandings of meanings, and this version of GT is equal to multiple social realities (Charmaz, 2011). CGT coding is inductive, comparative, interactive, and iterative and then deductive (Charmaz, 2012).

Ethics: ethical approval for research implementation was received from the Board of the Vytautas Magnus University (Lithuania).

Findings. Several categories were emerged within the context of ethical intellectual leadership in higher education. Seeking for quality and Seeking for meaningfulness were extracted as two interrelated categories in regard to the category of Retaining for scientist's reputation. The category of Being open in GT emerged as a context.

Conclusions. In evaluating practices that guide research endeavours, it is important to consider the individual character of scientific fields. Research fields that yield highly replicable results (such as ordinary organic chemical structures), are quite different from fields (such as cellular immunology), which are in a much earlier stage of development and accumulate much erroneous or not interpretable material before the pieces fit together coherently. When a research field is too new or too fragmented to support consensual paradigms or established methods, different scientific practices can emerge. A respectful work environment reduces the potential for conflict, increases morale and results in lower absenteeism and turnover. In turn, this creates a more productive environment for the employer and a friendlier place for employees to work. Having respect for colleagues earns the scientist respect in return, and creates an atmosphere where collaboration, trust and teamwork are valued.

---



# Poster Communications

## **Co-payments for unfunded additional care in publicly funded healthcare systems: ethical issues**

Joakim Färdow, Linus Broström & Mats Johansson  
Department of Clinical Sciences, Lund University, Sweden

Friday  
morning

Public healthcare systems face major challenges. The burden of resource constraints and continuous demands of rationings urge decision makers in countries like Sweden, Norway and the UK to find new financial solutions. One proposal that has been put forward is co-payment, where patients are given the option to pay the public healthcare provider for additional care, or more expensive alternatives, to that which is publicly funded.

In this presentation we explore ethical issues associated with co-payment in publicly funded healthcare systems, especially co-payment for services aimed at health benefits. The presentation will include a theoretical model of co-payment, and actual and hypothetical examples, for illustration. How authorities in countries where co-payment is being considered have chosen to deal with the issue will also be addressed. Finally, we shall critically discuss arguments for and against allowing for co-payment of the relevant kind.

---

## **Ethical Considerations in the Assessment of Risks in Social, Behavioral and Educational Research and the Role of the Ethics Committee or Institutional Review Board**

Colleen M. Gallagher  
University of Texas, Anderson Cancer Center

Saturday  
morning

The principle of justice in research generally involves two aspects: equitable selection of subjects in light of the burdens and benefits of the research and the protection of vulnerable populations. This presentation will consider the distinctions between these aspects in clinical trials and in social, behavioral and educational research. Through research protocol case examples in an interactive format we will apply considerations related to the setting, the population of possible subjects/participants, seven types of vulnerabilities and the protection or expectation of privacy in social, behavioral and educational research. Attention will be given to how an ethics committee or institutional review board can identify and assess if the risks have a balanced benefit/risk ratio through looking at magnitude and probability of the harms to subjects/participants specifically in social and behavioral research.

---

Saturday  
morning

## 4 years experience of Medicine and Literature Lecture Elective Course in Marmara University Faculty of Medicine

Sefik Gorkey & Orcun Cil

Department of Medical History and Ethics, Faculty of Medicine, Marmara University

Empathy is one of the most important component in patient-physician relationship. Medical education specialists use some technics to develop empathy ability for their students in educational levels. Narrative ethics is an option to develop empathy in physician-patient relationships.

We're realising elective course called "Medicine and Literature" in our "Department of Medical History and Ethics" for medical students year 1,2,3. Approximately 20 students attended this elective course. Course takes 1 semester, 3 hours a week.

Every week, students read 1 or 2 short stories, preferred but not limited to Turkish literature related with a medical topics (patients, patient-physician relationships, illnesses etc).

At the beginning of the course, every student write his/her expectations anonymously. After the course, we are taking a written feedback also anonymously.

---

Friday  
afternoon

## Ensuring the safety of participants of clinical trials

A. Khokhlov<sup>1</sup> & N. Chudova<sup>2</sup>,

<sup>1</sup> The Council on Ethics of the Ministry of Healthcare of the Russian Federation, Moscow, Russia, <sup>2</sup> FSBI "SCEEMP", Moscow, Russia

Introduction. Development of innovative drugs and various combinations of drugs, the study of a medicinal form or investigating the possibility of usage instruction expanding for previously registered drug products within the framework of clinical trials is based on the mandatory assessment of the safety profile by the Council on Ethics of the Ministry of Healthcare of the Russian Federation (CE). Members of CE evaluate preclinical studies results (the analysis of systemic toxicity and of specific toxicity of a drug) determine the ratio of potential benefits to risks for participants in the planned researches, and discuss the issues related to the ethical aspects of clinical trials.

Objective. To note the CE decisions to minimize the risks associated with patients participation in clinical trials of medicinal products.

Materials and methods. The expert work statistics of CE for the last year have been presented, examples of comments have been provided which may adversely affect the life and health of participants in clinical researches.

Results. During 2016 twenty-three meetings of CE took place, 1690 medical documents related to the conduct of clinical trials have been considered, among of which: 61% - initial submissions, 35% - the correction of the investigation dossiers, 4% - the responses to the comments of CE. 1582 assignments to conduct ethical expert examination have been approved, 108 - have been rejected.

The following observations of CE do not allow approving of a clinical trial Protocol:

- “inclusion of an educational establishment of the barracks type with nocturnal stay (The Kronshtadt Sea Cadet Corps) in the list of medical organizations is contrary to ethical standards”;
- “a very low threshold for The Hamilton Rating Scale for Depression was selected for inclusion of the patient in the study”;
- “the risks of relapse and a worsening of health conditions of the patient have not been specified in the case of falling into the placebo group, methods of exacerbations relief (especially in the outpatient setting) and to minimize the risks their development have not been described”;
- “the doses recommended for patients in the study exceed the doses with a certain toxicity for rats in an experiment, what is unsafe for patients”;
- “information on the expected timings of the phase 1b completion of clinical trials, safety assessments and reporting to chief researchers is not available”;
- “information on the period of time for which after the first introduction of a drug a patient must be observed in research center is not available”.

The cases of serious adverse events with a high degree of certainty of causal relationship with the studied drugs. Eight phone applications of patients/ healthy volunteers participating in clinical trials have been taken by CE. Methodical-scientific journal ”Medical ethics” is published quarterly with news and events dedicated to the current ethical and legal issues of participation in clinical trials.

Conclusions. CE is considering medico-ethical and legal issues, and taking measures to minimize the risk of patient involvement in clinical trials.

---

## On Socio-Psycho-Somatics in Medical and Juridical Philosophy

Friday  
afternoon

Michael Ch. Michailov<sup>1</sup>, Eva Neu<sup>1</sup>, Peter Birkenbihl<sup>1</sup>, Guntram & Edith Schulz<sup>1 2</sup>, Iva & Sonya Ivanova<sup>1</sup>, Michael Traub<sup>1</sup>, Ursula Welscher<sup>1</sup>, Janka & Viktor Foltin<sup>1 2</sup>, Manfred Holler<sup>1 3</sup>, Christoph Lütge<sup>1 4</sup>, Michael Schratz<sup>1 5</sup>, Germain Weber<sup>1 6</sup>

<sup>1</sup>Inst. Umweltmedizin (IUM) c/o ICSD/IAS e.V., POB 340316, 80100 M. (Int.Council Sci.Develop./Int.Acad.Sci. Berlin-Innsbruck-Muenchen-NewDelhi-Paris-Sofia-Vienna),

Muenchen, Germany; <sup>2</sup>Fac. Med., Univ. Bratislava, Bratislava, Slovakia; <sup>3</sup>Fac.

Economics, Univ.Hamburg, Hamburg, Germany; <sup>4</sup>Inst. Ethics (Dir.), Techn. Univ.

Muenchen, Muenchen, Germany; <sup>5</sup>School Educ. (Dean), Univ. Innsbruck, Innsbruck,

Austria; <sup>6</sup>Fac. Psychol. (Dean), Univ. Lxbg&Vienna, Vienna, Austria

Introduction. New conception about an integral anthropology (IA: 200 years after Immanuel KANT) describing human (individual-A) in interaction with nature-society (natural & social-A), building special-A. This is fundamental for general-A: philosophical-normative, pedagogical-educative, medical-curative/prophylactic (FISP-2008/10 - Seoul Proc.DVD/ISBN-13, 195-202/338-339/363-365. 2003-Istanbul 279-280. Proc. World-Congr. Philos. IVR-2015-Washington (Int.Ass.Philos.Law)

Progr. Book p.116/3,8,9,124/5, 127/3,129/3). Future socio-psycho-somatics in context of IA has a central position in medical sciences.

During Opening Ceremony of World Congr.Psychosom.Med. (ICPM-2005-Kobe) were present their majesties Emperor and Empress of Japan, Prime&Ministers for Science-Education-others & prominent scientists. Emperor AKIHITO honoured congress by strategical ideas, available for all health sciences, “total symptoms of mind&body, seeking ways of holistic care... it is extremely important for patients... my hope contributes... the progress of medical science and people’s happiness in the entire world”. (ICPM-2011-Seoul AB:p.167/186/189, ICPM-2005-Kobe Proc18, J PsychosomRes 58:p.85-6).

Method given in ISIM-2010-Melbourne, Internal-Med.J.40/1:144-5. EAN-2015-Berlin Eur.J.Neurol.22/S1, p.281,487-490,832. WFN-2016-Santiago-de-Chile, J.Neurol.Sci. 357/S1, no.183,187,199,234).

Results. Complex interaction of natural (micro-ecology in apartments), social factors are demonstrated by conflicts of residents/tenants with lessor (house-Munich n;50). Defect-doors & radiators, windows (air currents), etc. induce respiratory diseases, defect illumination supports accidents (neuro-orthopaedic: commotio cerebri, etc.). Conflicts conc. high rents, repair of apartments cause dangerous psychoneurological diseases (anxiety/neurosis-insomnia/depression, etc.), esp. in patients & seniors with angio-cardiac pathology (arrhythmia/hypertonic crisis, etc.), dementia, parkinsonism, acc. to Munich medical praxes of Drs. med. W.Baldauf, N.Duhr, C.Herdeis, M.Jung, E.Seibert, T.Seyfarth. Reports in German journals reflect catastrophic situation of tenant-lessor conflicts (tz-daily journal München: Interviews with law experts/Mieterverein Anja Franz, M.Vill, S.Immerfall, P.Irrgeher, H.Evers, Sigrid Reinthaler, A.Steiger, Beatrix Zurek, every Tuesday 2016). Observations on patients/probands were made about influence of psychosomatic therapy, esp. physical and psychic training by Indian medicine (music, body training) on psychic items.

Conclusion. An integrative therapy acc. to oriental somatopsychic-theory (Yujiro IKEMI) & self-regulation-practises: Yoga/Qigong/Zen-meditation, etc. with occidental psychosomatics (Th.von UEXKÜLL) combined with pharmaco-therapy could open new dimension in socio-psycho-somatic therapy as well as in medical philosophy, leading to new juridical norms for conflicts, i.e. between tenants/lessors supporting UNO-Agenda21 for better health, education, ecology on global level. EACME could integrate in future conferences regular topics about ethics and epistemology in psychosomatic medicine concerning new ideas and conceptions for better health care in this medical area.

Dedication for moral and scientific support of IUM-projects (2017-1980): Austria: Busek, Gornik, Lorenz\*, Belgium: Prigogine\*, Bulgaria: Balevsky, Juchnovski, France: Dausset\*, Lehn\*, Germany: Eigen\*, Kahn-Ackermann, Michel\*, Neher\*, Scheel, Simma, Stühmer, Vogel, J & Th von Uexküll, Weiss, GB: Josephson\*, Todd\*, India: Khorana, Srivastava, Singh, Japan: Fukui\*, Ikemi, Suematsu, Russia: Basov, D.-Danilyan, Filiov, Prokhorov, Spain: Lopez-Calera, Ochoa\*, Taiwan-China: Y.T. Lee\*, USA: Anderson, Deisenhofer, Pauling, Wiesel

## **Fragmented food autonomy: the meat industry as a social determinant of health and counter-capability factor**

Thursday  
afternoon

Cristian Moyano Fernández

Universitat Autònoma de Barcelona

Food is a basic human right recognized in article 25 of the Universal Declaration of Human Rights and, among other instruments of the international law, in article 11 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). However, about 20% of the world's population lives badly without having enough food to eat and without access to potable water. Now, malnutrition doesn't impact in the same way the whole population, but tends to jolt all considered third-world countries. Moreover, 80% of hungry children in the world live in countries with food surpluses, most in the form of animal feed which, in turn, will only be monopolized and consumed by the countries economically more developed. Paradoxically, one of the major epidemics that rich countries jolt are obesity and cardiovascular disease. According WHO analysis, currently, 18% of the world's total population is obese, practically the same number of malnourished people.

The meat industry is a phenomenon that causes some injustices due, on the one hand, to its factual and scientific unsustainability on a global scale; and, on the other hand, to the domination of a series of political, economic and socio-cultural paradigms. Need to think about it as an element that operates violating our autonomy and conditioning health public. The ethical Sen's capability approach facilitates an oncoming to this understanding since it takes into account the structural factors that influence our way of transforming goods and resources into welfare and freedom. This theory defends the primacy of capabilities and agency over life functions pre-established, because a respect for the first guarantees a minimum of autonomy and plurality; however, giving priority to specific operations, could cause an unwanted paternalism.

However, to what extent is consistency argued in favour of individual capability? I suggest that the liberal views of Sen and Nussbaum find a contradiction in the inequalities caused by the meat industry, so that it must be understood as a counter-capability rather than as a mere lack of capability. Making this leap supposes accepting the hypothesis that the defense of a capability can lead us to a situation of tragic choice, especially if we don't presuppose the existence of communities of meaning or collective capabilities. So that developing a capability sometimes indirectly leads to only to cancel the one of others but also the same own, only that understanding it intersubjectively even at an evaluative level, both collectively and individually. So therefore, my thesis consists on postulate that our food autonomy, which affects so much our own health, is fragmented by the social pressure of the meat industry, at the same time that the social inequalities rise. And such consequences aren't absorbed resolutely by the classical capabilities approach because they are due precisely to a structural raid for the development of agency freedom.

---

Thursday  
afternoon

## **Exploring the ethical issues of growth hormone treatment for idiopathic short children as a case of medicalisation**

Maria Cristina Murano  
Linköping University

In 2003, the Food and Drug Administration approved the use of growth hormone treatment for idiopathic short stature children, i.e. children shorter than average due to an unknown medical cause. This decision has been a matter of debate as there is no agreement on whether and when short stature should be treated.

In this presentation, I investigate the ethical issues of growth hormone treatment for idiopathic short children, using medicalisation as a framework of analysis. To do that, I combine literature on bioethics, medical sociology, philosophy of medicine, and academic medical articles. After the clarification of my understanding of medicalisation and the description of the treatment, I take the medical-nonmedical distinction and the debate about the goals of medicine as the point of departure to problematise the ethical analysis. I then discuss different levels of normativity of medicalisation, and I finally stress the need not only to evaluate individual cases at different levels, but also to conduct further research on the long-term safety of the treatment, on the experience of extremely short children, on the common perceptions of short stature and on the best ways to involve children in decisions concerning the treatment.

---

Friday  
morning

## **Utilitarianism and Egalitarianism in Organ Allocation**

Piotr Grzegorz Nowak  
Jagiellonian University

Organs for transplant are scarce goods. Therefore each decision about allocating graft to one patient involves death or suffering of the other who cannot receive it. But such decisions just have to be taken, and we expect them to be made in accordance with reasonable moral theory. In the presentation I will try to formulate the general organ allocation theory which could satisfy that condition.

The acceptable theory of allocation should be pluralistic, so it should be influenced by all moral ideals that are important in that specific context. Presented theory will account for two different concepts of justice. Both of them will be understood as some kind of concretisations of Aristotelian principle of distributive justice which states that “ (...) [D]istribution is just to the extent that the value of the thing it assigns to one person stands to the value of the thing it assigns to another as the worth of the one person stands to the worth of the other” (Keyt 1991, pp. 240-241). This purely formal principle does not determine yet what kind of worth is a proper standard of comparison between different people.

Effectiveness understood as an ability to use resources in order to obtain welfare is a standard of comparison for utilitarian concept of justice. In the context of organ distribution utilitarianism confers an equal claim to receive graft for people who can make use of them equally effective and different claim for people that differs

in effectiveness. Accordingly, if it is possible to obtain either 5 units of welfare if Abby receives liver or 10 units if it goes to Betty, it would be fair to allocate the transplant to Betty. However if both Abby and Betty are able to obtain equal quantity of welfare, then utilitarian theory of justice would confer both of them equally strong claim to receive the transplant

Luck egalitarians are interested in the ratio between deserts and wellbeing of each person. They say that the claim to receive the transplant should be assigned in the proportion to that ratio. Let me now come back to the problem of making a decision on organ allocation either to Abby or Betty. If Abby already had 10 units of desert and 1 unit of wellbeing, and Betty had 1 unit of desert and 10 units of wellbeing, then, according to luck egalitarianism, stronger claim should be assigned to Abby, because in her case the ratio between deserts and wellbeing equals 10, while for Betty the ratio equals 0.1. From the luck egalitarian perspective it does not matter that Abby could use received transplant in the future more effectively than Betty, obtaining 10 units of welfare instead of 5 units.

The reasonable theory of organ allocation should account for both of these competing concepts of justice. The main purpose of the paper would be to assign adequate weight to each concept as well as to operationalise both of them, so that they might be applied to design particular rules for organ allocation.

References: Keyt, David. 1991. *A Companion to Aristotle's Politics*, Cambridge: Blackwell.

---

## The “time of waiting”: the Nurse and the end-of-life choices in the Neonatal Intensive Care Unit

Friday  
afternoon

Renzo Pegoraro

Fondazione Lanza, Padova; Pontifical Academy for Life, Rome

The nurse has the responsibility of assisting, treating and taking care of the person, with respect for the life, health, liberty and dignity of the individual (Italian Professional Code of Nurses). All of this requires special attention and application when treating a newborn, keeping in mind his/her fragility and vulnerability and then the level of maturity.

To confront end-of-life decisions, some ethical values and principles like the following are important:

- The centrality of the patient and the recognition of his/her dignity, in any situation or condition in which he/she may be.
- The integral good of the person, considering the physical, psychological, spiritual and relational dimensions
- The value and protection of human life.
- Responsibility of the sick person. In the neonatal area the responsibility belongs to the parents, and so the familial context and relationships are important; it is necessary that appropriate and complete information be given to parents about the situation of the neonate.

- The importance of “treating” and “assisting” in the effort of adequately attending to these fundamental ethical experiences. The nurse participates in the decisions of the clinical team, involving the parents and, as far as is possible, the minor, and accompanying them in the end-of-life phase with palliative care and comfort.
- Specific role in prevention and relief of pain and suffering.
- The proportionality of the treatments, to avoid forms of aggressive medical treatment or euthanasia; the concept of therapeutic proportionality is fundamental in the medical practice. One should not “medicalize” where it is not necessary, simply for int
- Also, reference to the values of justice and solidarity should always be present.

There is a challenge in cultivating a relationship between “hopes” and “Hope,” with a “meaning” that sustains a hope that is still glimpsed when one has reached the point of being unable to be cured.

We need a change in the approach that combines high technology with high empathy and continuous dialogue with parents in order to give meaning to the “time of waiting” before recovery or towards the end of life, always emphasizing the idea of “care” in the holistic sense.

## **Nuevo abordaje del control de la Hidradenitis Supurativa (HS), enfermedad crónica de gran repercusión psicológica y socio-laboral desde una Unidad Multidisciplinar y la Voz de los pacientes: Reflexión Ética sobre el “Barómetro social” de esta enfermedad**

Thursday  
afternoon

Cristina Pelufo & Antonio Martorell

Comité de Bioética Asistencial (CBA) del Departamento de Salud de Manises- Valencia, Asociación Española de Enfermos de Hidradenitis (ASENDHI), Servicio de Dermatología del Hospital de Manises

Introducción. La HS es una alteración folicular que impacta notablemente en la vida de los pacientes. Afecta a las áreas corporales con presencia de glándulas apocrinas, sobre todo axilas, ingles, pliegue submamario y glúteos. Se manifiesta con abscesos, foliculitis, granulomas progénicos, comedones, tractos fistulosos y queloides.

Se cree que en la enfermedad subyace un desequilibrio inmunológico en una persona predispuesta genéticamente. El diagnóstico y tratamiento han cambiado notablemente en los últimos años, siendo multimodal y multidisciplinar

La encuesta poblacional realizada ha sido de gran ayuda para llevar a cabo nuevas estrategias diagnósticas y terapéuticas mejorando tanto los resultados, el grado de satisfacción de los pacientes como la percepción social de la misma, aspectos que responden tanto a CRITERIOS DE UTILIDAD SOCIAL como a RESPONSABILIDAD en SALUD

Metodología.

1. Encuesta Nacional de la Asociación de pacientes de Hidradenitis (ASENDHI).  
Principales parámetros valorados:

- población afecta por sexo/edad/situación laboral
- obesidad y tabaco
- tiempo transcurrido antes del diagnóstico y tratamientos recibidos
- días de estancia hospitalaria y número de cirugías
- repercusión psicológica y social
- grado de satisfacción de la atención recibida
- costes económicos

2. Reflexión Ética (Comité de Bioética Asistencial, CBA)

Resultados. La edad de los pacientes afectados de HS está entre 21-50 años (87%), con un predominio de mujeres, un 30% son desempleados, sólo el 16,9% tienen un índice de masa corporal normal, un 61,7% son fumadores y el 24,2% son ex-fumadores, en más del 30% hay antecedentes familiares de HS, el diagnóstico se ha demorado hasta la severidad de la enfermedad y tras varias cirugías y un 30% no están satisfechos con la asistencia recibida hasta entonces. Los datos epidemiológicos recogidos en la Guía Europea de HS son similares a los que recoge esta encuesta.

El CBA, en base a estos resultados, establece una interrelación entre la ética principialista y la social observando posibles mejoras en el control de la enfermedad desde un equipo multidisciplinar, respetando la autonomía y cuidando vulnerabilidad de los pacientes y control eficacia/costes.

Conclusiones:

- Necesidad de un equipo multidisciplinar (médico, psico-social e institucional) en el control de la enfermedad
  - Demoras diagnósticas y terapéuticas son determinantes de salud negativos a corregir para conseguir un mejoramiento social
  - Estilos de vida y diferentes opciones terapéuticas son determinantes en el control de la enfermedad
  - Considerar al paciente desde su VULNERABILIDAD y AUTONOMÍA agente activo en responsabilidad, sensibilidad y control de su enfermedad
  - Necesidad de un equipo multidisciplinar (médico, psico-social e institucional) en el control de la enfermedad
  - Demoras diagnósticas y terapéuticas son determinantes de salud negativos a corregir para conseguir un mejoramiento social
  - Estilos de vida y diferentes opciones terapéuticas son determinantes en el control de la enfermedad
  - Considerar al paciente desde su VULNERABILIDAD y AUTONOMÍA agente activo en responsabilidad, sensibilidad y control de su enfermedad
-

Saturday  
morning

## Mejora de la Calidad Docente en Cuidados Paliativos

Emanuele Valenti<sup>1</sup>, Tayra Velasco<sup>2</sup>, Benjamín Herreros Ruíz-Valdepeñas<sup>1</sup>, Beatriz Moreno<sup>3</sup>, Cristina Coca<sup>4</sup> & Eduardo Pacios<sup>1</sup>

<sup>1</sup>Facultad de Ciencias Biomédicas, Universidad Europea; <sup>2</sup>Facultad de Enfermería, Fisioterapia y Podología, Universidad Complutense de Madrid; <sup>3</sup>Hospital La Fuenfría; <sup>4</sup>Universidad Autónoma de Madrid

**Objetivo:** El objetivo del proyecto consiste en desarrollar un recurso digital disponible on line en abierto sobre medicina paliativa con el fin de desarrollar contenidos didácticos sobre procedimientos estándar en cuidados paliativos.

**Metodología:** Se desarrolló una revisión sistemática de la literatura científica sobre cuidados paliativos. El proyecto está dirigido hacia los siguientes grupos:

- Docentes y estudiantes de medicina
- Profesionales de la salud
- Trabajadores sociales y otros profesionales relacionados con la medicina paliativa (hospitales, residencias, asistencia domiciliar)
- Profesores de idiomas en Facultades e Instituciones sanitarias
- Empresas que operan en los servicios sociales

**Resultados:** Tras la revisión de la literatura se desarrolló una guía práctica sobre los principales procedimientos estándar en cuidados paliativos; También se elaboraron Vídeos con simulaciones de los procedimientos contenidos en la guía. Se dispuso de recursos lingüísticos para potenciar la comunicación en la medicina paliativa. Se desarrollaron 2 cursos on line en abierto; 1 curso sobre el lenguaje de la medicina paliativa y 1 curso sobre procedimientos clínicos en cuidados paliativos.

**Conclusiones:** El uso de material didáctico para docentes y formadores en cuidados paliativos sobre procedimientos estándar ayuda a potenciar las habilidades de comunicación de los docentes, estudiantes y profesionales de la medicina en el área de los cuidados paliativos.

---

# Author Index

- Acheson Elaine, 8, 91  
Aiguier Grégory, 59  
Albertsen Andreas Brøgger, 9, 17  
Aleksandrova-Yankulovska Silviya,  
10, 11, 15, 44  
Almutairi Faisal, 12  
Alonso Valcárcel Mònica, 110  
Aluas Maria, 13  
Amarnani Raj, 14  
Anov Atanas, 15  
Anuzis Aivaras, 119, 120  
Astete Carmen, 16, 64  
Avila Silvina, 7  
Ayza Pérez Olga, 110
- Bærøe Kristine, 17–19  
Barnett Pauline, 12  
Bassford Chris, 103  
Beca Juan Pablo, 20  
Belyaletdinov R. R., 21  
Biller N., 116  
Birchley Giles, 21  
Birkenbihl Peter, 125  
Blazeby Jane, 21  
Bodiroga Vukobrat Nada, 46  
Boer Bert, 54  
Brall Caroline, 118  
Brinchmann B. S., 50  
Bringedal Berit, 19  
Broström Linus, 123  
Brunet Laurence, 33  
Buchholz Ines, 98  
Buchholz Maresa, 98  
Buyx Alena, 85
- Caenazzo Luciana , 23  
Camus Agathe, 57  
Cappelen Cornelius, 17
- Carlsen Benedicte, 18  
Carlsson Andreas Brekke, 17  
Carreras Marcos B., 39  
Castagnoli Andrea, 24  
Chernykova A., 79  
Chudova N., 124  
Cil Orcun, 25, 124  
Clercq Eva De, 28, 92  
Coca Cristina, 132  
Colchero Calderón M<sup>a</sup> Constanza, 25  
Cornejo Jesús, 82  
Corsano B., 94  
Corsico Paolo, 27  
Costa Mateu Joan, 71  
Craxì L., 93
- de Bont Antoinette, 54  
de Snoo-Trimp J. C., 50  
de Vet H. C. W., 50  
Degrie Liesbet, 29  
Denier Yvonne, 2, 29  
Deplazes Zemp A., 116  
Dierckx de Casterlé Bernadette, 29  
Duersteler Kenneth, 84  
Dunn Michael, 30
- Eiroa-Orosa Francisco José, 31  
Elger Bernice, 8, 28, 91, 92  
Emilia Ova, 102  
Epozturk Kursat, 25  
Esquerda Montserrat, 82, 118  
Ettema Eric, 111
- Färdow Joakim, 123  
Førde Reidun, 62  
Foltin Janka & Viktor, 125  
Fourie Carina, 32  
Fournier Véronique, 33

Fox Susan, 33  
 Gías Gil Belén, 110  
 Gámez Sergio, 38  
 Gómez María Inés, 42, 64  
 Gabaldón Fraile Sabel, 34  
 Gaille Marie, 36  
 Gallagher Colleen M., 123  
 Galvagni Lucia, 37  
 Ganguli-Mitra Agomoni, 37  
 García Caballero Rebeca, 38  
 Garcés Domingo Marc, 110  
 Garcia Naranjo Ignasi, 110  
 Garcia Terol C., 39  
 Gasparetto Alessandra, 40, 105  
 Gastmans Chris, 29  
 Gather Jakov, 98  
 Gilart de Keranflec'h Charlotte, 41  
 Gorkey Sefik, 25, 124  
 Graells J., 90  
 Grebenshchikova Elena, 43  
 Gregori Roig Pasqual, 7  
 Griffiths Frances, 103  
 Grigorova Antonia, 44  
  
 Hadiano Tridjoko, 102  
 Haltaufderheide Joschka, 96  
 Hartman L. A., 45  
 Hermann Helena, 49  
 Herreros Ruíz-Valdepeñas Benjamín,  
     38, 132  
 Holler Manfred, 125  
 Horak Hana, 46  
 Horn Ruth, 46  
 Howes Noah, 21  
 Huxtable Richard, 21  
  
 Illa Mestre Marc, 47  
 Inguaggiato Giulia, 48  
 Ireo Eghoiunu, 49  
 Iseli Luzia, 49  
 Istvan Gamberoni Piffer, 82  
 Ivanova Iva & Sonya, 125  
 Ives Jon, 21  
  
 Jamouille Marc, 4  
 Jaso Tejera Raquel , 109  
 Jimeno Sonia, 52  
  
 Johansson Mats, 123  
  
 Kavas Mustafa Volkan, 114  
 Kennedy Mari-Rose, 53  
 Kerasidou Angeliki, 54  
 Khokhlov A., 124  
 Kingori Patricia, 54  
 Kirk Ray, 12  
 Kleinhout-Vliek Tineke, 54  
 Kohlen H., 55, 112  
 Kostova Maria, 11  
 Krawczak Michael, 85  
 Kremer Swanny, 56  
 Kroon Duco, 56  
 Kubheka Brenda, 57  
  
 Lütge Christoph, 73, 125  
 La Valle Ricardo, 4  
 Lancelot Mathilde, 57  
 Landeweer Elleke, 58  
 Le Berre Rozenn, 59, 60  
 Leget Carlo, 61  
 Lesovoy V., 79  
 Lieb Wolfgang, 85  
 Lillemoen Lillian, 62, 63  
 Luco Lorna, 16, 42, 64  
 Luków Pawel, 65  
  
 Maglio Milena, 66  
 Manjure Sanjiv, 81  
 Martín Badia Júlia, 66  
 Martin Rodrigo R., 39  
 Martinez Becerro Esther , 109  
 Martorell Antonio, 130  
 Maylenova Gabelhakovna Farida, 35  
 Maza Andrea, 7  
 McLane Hannah, 67  
 Meleiro Trillo E., 39  
 Mellen Teodor, 68  
 Mendieta Maximiliano, 69  
 Metselaar Suzanne, 48  
 Michailov Michael Ch., 73, 125  
 Michaud Patricio, 42  
 Minacori R., 93, 94  
 Molewijk Albert Christiaan, 45, 50,  
     56, 111  
 Montaguti Elena, 70, 105

Moreno Beatriz, 132  
 Moyano Fernández Cristian, 127  
 Muñoz D., 90  
 Murano Maria Cristina, 128  
 Myroshnychenko Mykhailo, 78, 79  
  
 Nadolny Stephan, 96  
 Nakazawa Akira, 72  
 Neu Eva, 73, 125  
 Nicoli Federico, 70, 74, 82, 105  
 Nowak Piotr Grzegorz, 128  
  
 Onal Gulsum, 75  
 Orce Gabriel, 77  
 Ospanova Tetyana, 78, 79  
 Oswald Albert, 73  
 Ouvrard Patrick, 4  
  
 Pérez Capellades Rosa M<sup>a</sup>, 80  
 Pérez Pinedo I., 39  
 Pacios Eduardo, 132  
 Pacurari Nadia, 8  
 Parellada N., 90  
 Pegoraro Renzo, 129  
 Pelufo Cristina, 130  
 Phaily Ary, 81  
 Picozzi Mario, 74, 82, 105, 113  
 Pifarré Josep, 82, 118  
 Pizzanelli Miguel, 4  
 Popova Olga, 107  
 Porz Rouven, 48, 118  
  
 Rakic Milenko, 91  
 Ramponi Jean Pierre, 74  
 Razai Mohammad, 83  
 Real de Asúa Diego, 38  
 Refolo P., 93, 94  
 Reichstein Angelika, 84  
 Reiter-Theil Stella, 84  
 Reus Calvo E., 39  
 Ricciardeli P., 39  
 Richter Gesine, 85  
 Riera Armengol Laia, 87  
 Rigo Adelheid, 88  
 Ritzenthaler Daniela, 89  
 Robles Bernabé, 90  
 Roig Carrera Helena, 68  
 Román-Maestre Begoña, 3  
  
 Rost Michael, 8, 91, 92  
 Ruiz Montilla María José, 71  
  
 Sánchez Thevenet Paula, 7  
 Sævareid Trygve Johannes Lereim, 62  
 Sacchini D., 93, 94  
 Salloch Sabine, 95, 98  
 Schildmann Jan, 96  
 Schmidt Kurt W, 97  
 Scholten Matthé, 98  
 Schramme Thomas, 1  
 Schratz Michael, 73, 125  
 Schreiber Stefan, 85  
 Schuermann Jan, 84  
 Schulz Guntram & Edith, 125  
 Seidlein Anna-Henrikje, 98  
 Senn Tatjana, 73  
 Sheehan Mark, 100  
 Shevchenko Sergey, 100  
 Silva Cristian, 7  
 Slowther Anne, 103  
 Soler Jorge, 118  
 Sorokina Iryna, 78, 79  
 Souto Monica , 7  
 Spagnolo A. G., 93, 94  
 Spranzi Marta, 101  
 Spreen Marinus, 56  
 Stainov Rumen, 73  
 Stappen Ralf K., 73  
 Stuy Johan, 88  
 Suhoyo Yoyo, 102  
 Svantesson-Sandberg Mia, 50, 103  
  
 Tamin Jacques, 104  
 Teig Inger Lise, 18  
 ter Meulen Ruud, 53  
 Testa Jacopo, 105  
 Tham Joseph, 106  
 Thomas John, 81  
 Thoresen Lisbeth, 62  
 Tishchenko Pavel, 107  
 Tornel Cerezo María, 71  
 Torrell Vallespín Gemma, 87, 108  
 Torres Cayuelas Queralt, 110  
 Totushek Nate, 67  
 Tozzo Pamela, 23  
 Trachsel Manuel, 49

Tramunt M., 90  
Traub Michael, 125  
Tsyzman L., 124  
Tudela Cantallops Lourdes, 110

Ulman Yesim Isil, 75  
Unzurrunzaga Diaz Ainhoa, 109  
Ursin G., 50  
Uzoho Chudy, 81

Valenti Emanuele, 38, 132  
Valls P., 90  
van Melle Laura, 111  
van Nistelrooij A. A. M., 55  
van Nistelrooij I., 112  
Vega Gala, 38  
Vekov Toni, 10  
Velasco Tayra, 132  
Viñas Joan, 118  
Viganò Vittoria, 113

Vogel Marc, 84  
Vollmann Jochen, 96, 98  
Voskes Yolande, 111, 115

Wäscher S., 116  
Wangmo Tenzin, 8, 49, 91, 92  
Wankel Heike, 73  
Weber Germain, 73, 125  
Welscher Ursula, 73, 125  
Widdershoven Guy, 48, 50, 111, 115  
Widmer Daniel, 4  
Wild Verina, 117  
Willi Benjamin, 118  
Wolff Lena, 85

Yordanov Nikolai, 11  
Yudin Boris, 43  
Yuguero Oriol, 118

Zaozerskaya N., 79  
Zydziumaite Vilma, 119, 120